DOLENTIUM HOMINUM
N. 22 (Eighth Year - No. 1) 1993
JOURNAL OF THE PONTIFICAL COUNCIL FOR PASTORAL ASSISTANCE TO HEALTH CARE WORKERS

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Published three times a year

Subscription rate:
one year Lire 60,000
(abroad $ 60 or the corresponding amount in local currency postage include)
The price of this special issue is L. 60.000 ($ 60)

Printed by
Vatican Press

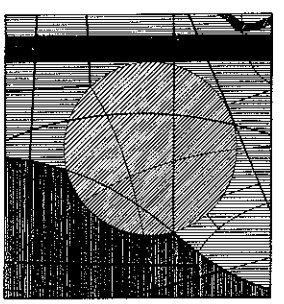
Sped. in abb. post. gr. IV/70%
I Quadrimestre 1993
N. 22 (Anno VIII - N. 1) 1993

Proceedings of the Seventh International Conference

organized by
The Pontifical Council for Pastoral Assistance to Health Care Workers

Disabled Persons in Society

November 19-20-21, 1992



Paul VI Hall
Vatican City

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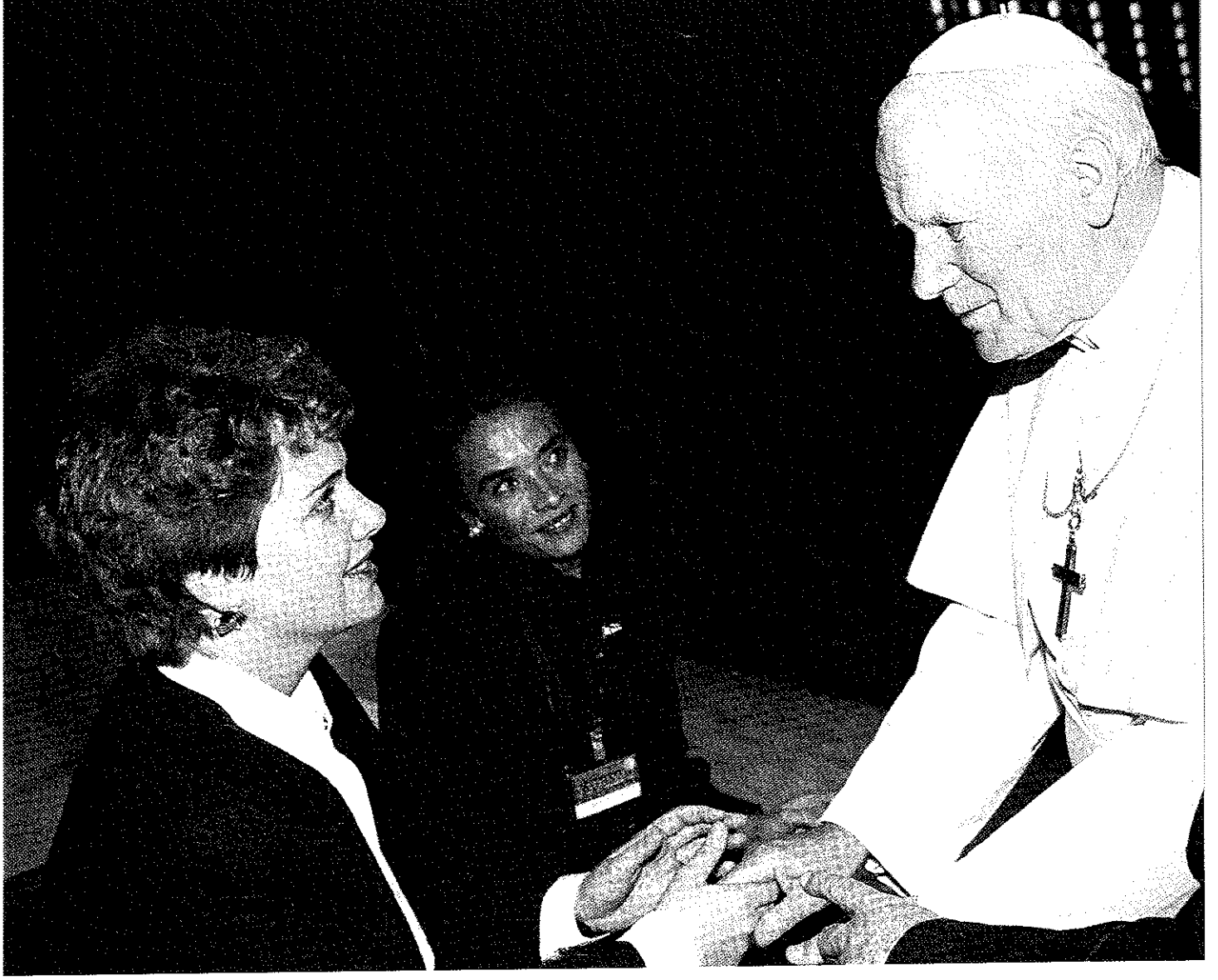
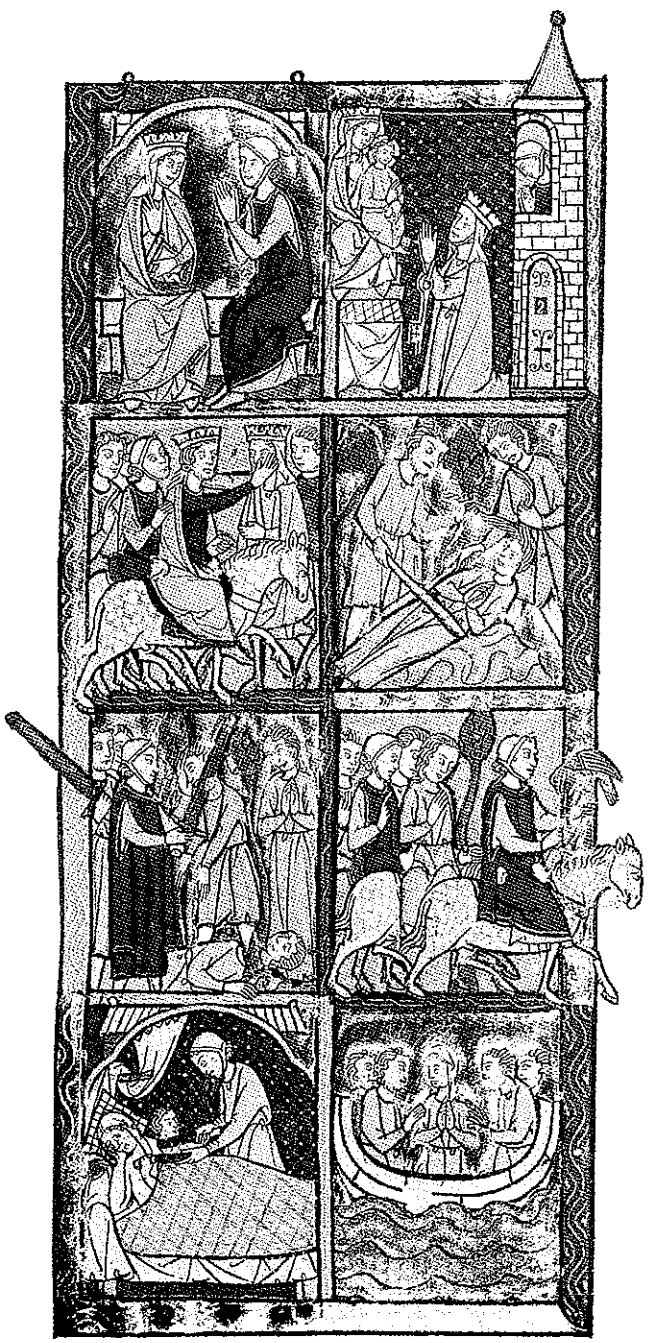
The illustrations have been taken from the volume
Les manuscrits enluminés français du XIII siècle dans les collections soviétiques, 1270-1300
(Moscow, 1984)



" *A handicap, any form of handicap,* never affects the dignity of the person *or his right to the best quality of life.*

" *'You are members of the Body of Christ': the body of the Risen One! This is the true foundation for an indestructible dignity! A dignity which withstands even the dominion of death. It has in fact been said that this corruptible body of ours will be robed in incorruptibility; 'this mortal body of ours will be robed in immortality' (cf.* 1 Co *15:52).* "

Cardinal Angelini's Words to the Holy Father



Holy Father,

I extend to you, and may you receive, a most heartfelt welcome from us all.

This International Conference, which follows its six predecessors, for the first time is to take place in a hall where you, Holy Father, have held your great meetings with people from every country in the quest for true and effective care and tutelage of the spirit. These conferences have met with a growing interest and have commanded increasing attention; they have given rise to manifold, dramatic, and yet confident proposals.

This meeting, which takes place on the eve of the liturgical solemnity of Christ the King, gives us the strongly-felt hope that this celebration of the Lord will be a sign of courage in life, especially for those who share with Christ, more closely, the hour of Gethsemane.

All those who are present now, Holy Father, wish to engage in a hymn to faith, to hope, and to love; they want to sing to life. Even if the expressions of religious life are different, faith in life and in its foremost value is faith in the " living " God.

In listening to your words, we hope, Holy Father, that the activities of the Pontifical Council for Pastoral Assistance to Health Care Workers have served to shake the conscience of the world as regards the most serious and urgent problems and difficulties of disabled people. These are questions of justice and of the true dignity of each person.

As in previous years, your message will be the highest expression of our work, a sign that the Church lives out her own salvific nature within the community of pain.

Thank you, Holy Father, for your words. With you, all of us together truly feel members of the Body of Christ.

FIORENZO Cardinal ANGELINI
President of the Pontifical Council for Pastoral Assistance to Health Care Workers

ADDRESS BY THE HOLY FATHER

The Disabled Have the Right to Be Accepted into Society and to Assume Responsibility for Their Own Lives

1. *I am pleased to be able to address my greeting this year as well to participants in the International Conference organized and prepared by the Pontifical Council for Pastoral Assistance to Health Care Workers, whose theme is "Your Members Are the Body of Christ. Disabled Persons in Society."*

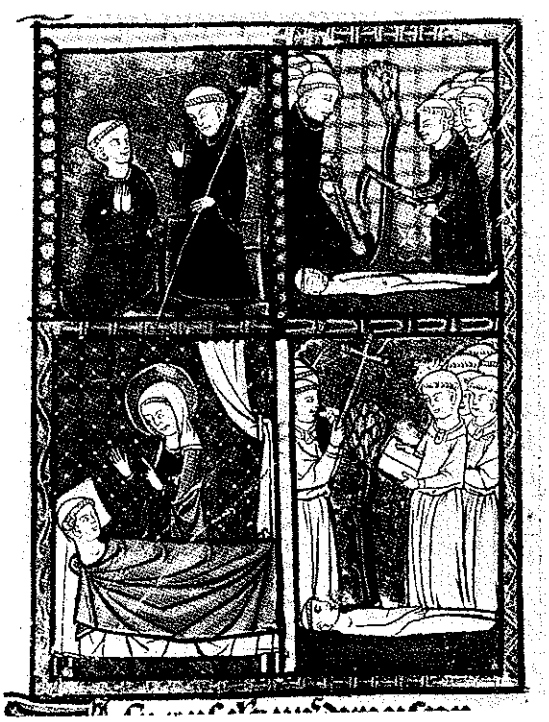
This annual appointment for reflection and study, while arousing growing interest in the different sectors of society, increasingly aims to be an occasion bringing together for a fruitful exchange of experiences those involved in the search for adequate means to solve the most serious problems afflicting a great part of the human race.

With gratitude I greet the distinguished guests called here from different nations—scientists, researchers, physicians, sociologists, theologians, scholars, and health professionals—who offer the contribution of their investigations and their experiences, brought to maturity over years of diligent, responsible dedication.

I particularly greet Cardinal Fiorenzo Angelini, the active President of the Pontifical Council, and his coworkers, along with those who in varied capacities have contributed to the success of this important International Congress.

2. *The problem of the disabled is common to all countries. There are, indeed, about five hundred million physically and psychically handicapped people, but many of these, unfortunately, still do not benefit from the necessary services. Risk factors and serious obstacles to readaptation are especially observed in the developing countries, where, according to some authoritative data, 85% of the disabled live and where a high percentage of handicaps—blindness, for example—is caused by endemic diseases and subhuman health conditions. Frequent conflicts and natural calamities have multiplied their number. I am particularly thinking of children, women, and the elderly, as well as the serious conditions in which considerable groups of disabled fugitives and refugees live. In industrialized countries, too, the number of handicaps, fostered by the spread of models of development which deny or disregard the dignity of the human person, is elevated and in some regions even on the increase. Let it suffice to recall the consequences of accidents on the road and in unprotected work and of the abandonment and neglect of minors.*

In addition, many of the handicapped—fragile and often disturbed by awareness of their disability—feel ignored in their difficulties and are in fact spurred to lead a marginalized life. Public opinion, while devoting space and attention to subjects, fashions, and customs which are



sometimes ephemeral, does not show all the interest due such a serious problem.

Praiseworthy initiatives are not lacking, however, which aim to make society more sensitive to these problems and support the handicapped in overcoming their condition of marginalization and incorporating themselves fully into the community. The legislation of many nations has made notable strides in this regard, promoting a culture of receptiveness through diligent, bold choices and fostering the progressive social integration of these persons.

3. *In your lessons and reflections, in the exchange of experiences and opinions during these days, you have also studied the subject of the disabled, examining its anthropological, clinical, moral, technical, social, juridical, and religious aspects. You have pointed out that, in the context of a rediscovered social and health-care awareness, it is possible, with the help of science and technology, to provide better social and medical assistance, satisfying the varied needs and exigencies of the disabled and often preventing as well the very rise of physical or psychic handicaps.*

If in this field much has been done, though in the midst of difficulties and obstacles, much still remains to be done so that the cultural, social, and architectural barriers keeping the disabled from satisfying their legitimate aspirations will be definitively overcome. It is necessary to act in such a way that they can feel welcomed into the civil community by full right, being accorded the effective opportunity to play an active role in the family, society, and the Church. Discretionary assistance, then, entrusted to the generosity of some, is not enough; it is necessary for there to be responsible involvement at different levels by all the members of the community.

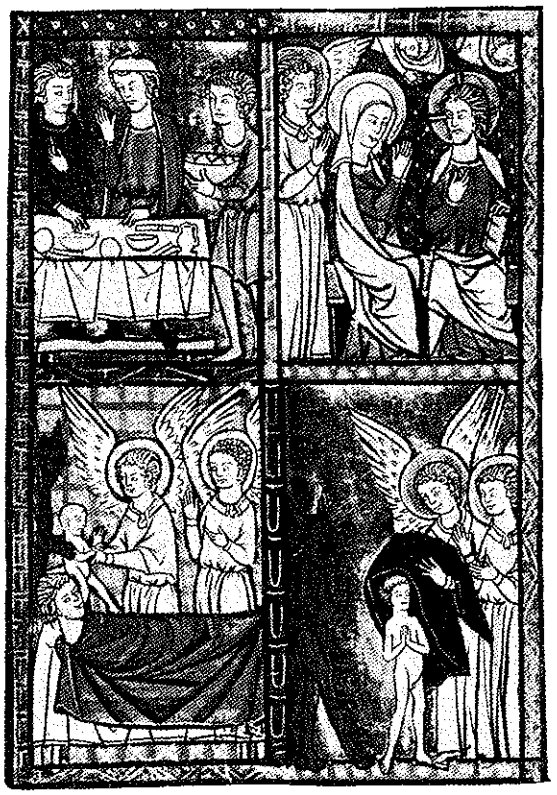
4. *Every human person—as international legislation clearly recognizes—is the subject of fundamental rights which are inalienable, inviolable, and indivisible. Every person—therefore, the disabled as well. On account of their handicap, however, they may encounter special difficulties in the concrete exercise of such rights. They thus need not to be left alone. No one better than a Christian is able to grasp the duty of this altruistic action. The Christian is, in fact, reminded by St. Paul, speaking of the Church, the Mystical Body of Christ, that "if one member suffers, all the members suffer with him" (*1 Co *12.26). This revelation sheds heavenly light upon human society as well and leads us to understand that within structures solidarity must be the true criterion regulating relations among individuals and groups. Man, every human being, is always worthy of maximum respect and has the right to express his or her dignity as a person fully. In this perspective, the family, the State, and the Church—each in the sphere of its own nature and tasks—are called in their different articulations to rediscover the greatness of man and the value of suffering, "present in the world to release love..., to transform all of human civilization into the civilization of love" (*Salvifici Doloris, *30).*

The family, the State, and the Church—the structures supporting human life in community—are asked to make a special contribution so that the culture of solidarity will develop and the handicapped may take on a leading role in their own lives.

The family, above all, which is the sanctuary of love and understanding, is called to share the condition of the weakest more than anyone else, to rediscover its decisive role in the training of the disabled, with a view towards their physical and spiritual recovery and their effective integration into society, which constitutes the natural place for their maturation and harmonious growth towards the personal and emotional balance that is indispensable to establish adequate contacts and relations with others.

Furthermore, an equally important task is the responsibility of the State, whose level of civiliza-

tion is measured by the standard of the respect with which it is able to surround the weakest among the members of society. This respect must be expressed in working out and offering strategies for prevention and rehabilitation, in seeking and implementing all possible pathways to recovery and human growth, in promoting integration into the community with full respect for the dignity of the person, fostering in the disabled—as I have previously recalled—" participation in the life of society in all its dimensions and at all the levels accessible to their capacities: family, school, work, and the social, political, and religious community " (Insegnamenti di Giovanni Paolo II, *vol. VII/2, 1984, p. 398)*



The Church also has the duty and right to intervene in this delicate area; guided by the example and teaching of her Lord, she has never ceased to do her utmost to serve the weakest. Let it suffice to point to the numerous and meritorious religious institutions of men and women, in addition to the associations of lay faithful which have arisen over the centuries with the specific charism of the care of the handicapped. This attention to the needy must increasingly involve the whole Church community, so that everyone —and particularly the person in difficulty—may attain full integration into the life of the family of believers. To the disabled I reiterate here the message formulated by the Special Assembly of the Synod of Bishops in 1987: " We are counting on you to teach the whole world what love is " (" Messaggio al Popolo di Dio, " no. 13, in L'Osservatore Romano, *Oct. 30, 1987, p. 4).*

5. *In addition, deserving of appreciation and gratitude are the efforts made by the World Health Organization (WHO) and other United Nations bodies and the action carried out for many years now in this field for research into the causes of disabilities, information and meetings for study, interregional consultation, the coordination and development of services, the promotion of readaptation, and the education and professional training of health, educational, and social service personnel.*

Heartfelt approval should also be conveyed to the United Nations for having proclaimed, on October 14th, an international day for disabled persons, establishing that it will be held each year on December 3rd. A provident initiative opportunely taking its place alongside the World Day of the Sick, which the Catholic Church, starting next February 11th, will hold annually on the day dedicated to Our Lady of Lourdes. Its purpose is to prompt in believers and all sensitive people a more intimate sharing in the sufferings of every human being, regardless of race, culture, or religion, stimulating public opinion as far as possible towards greater attention to suffering man with a view towards more effective service to life.

Furthermore, how can we fail to recall the contribution made to this cause by nongovernmental and professional organizations and the wonderful contribution offered by volunteers, with a presence which has in many instances revealed itself to be decisive in solving even complex human problems? I would therefore like to give credit to the numerous volunteers who, in a praiseworthy spirit of service, gratuitously offer their resources, their time, and their availability to meet the needs of the disabled. I encourage them from my heart to continue in their action, which is at once an eloquent witness to faith and a singular experience of a direct encounter with Christ, present in the persons tried by illness (cf. Mt *25:40).*

6. *Nor would I like to leave out the task of science and medicine, called to join their efforts to improve the physical conditions of the disabled and increase in them the hope of recovery and of active incorporation into society. Scientists, physicians, nurses, and technicians are called to do everything possible to humanize therapeutic assistance, well knowing that, in the handicapped, physical limitation and*

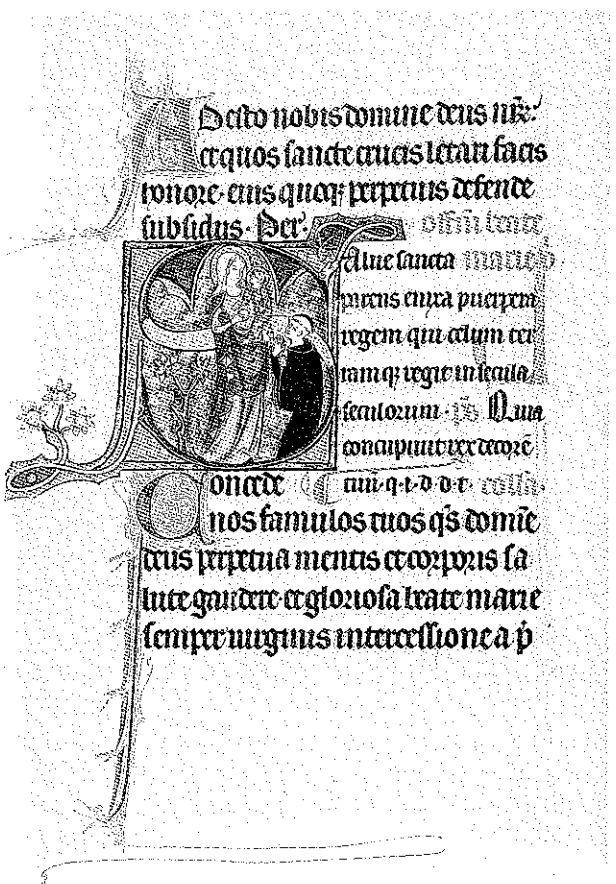
psychic difficulty require converging, responsible commitment on the part of all.

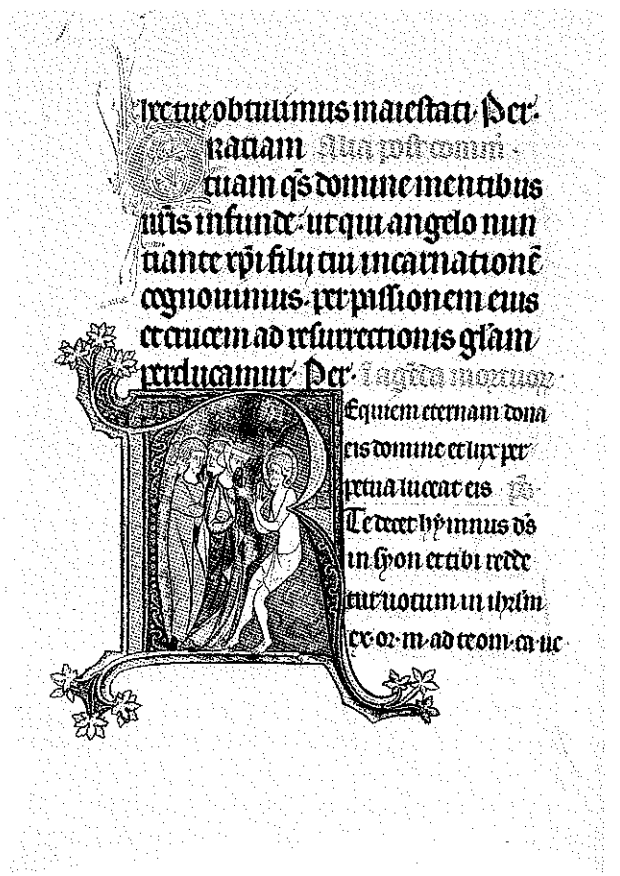
7. *The words accompanying the topic of this International Conference—" Your Members Are the Body of Christ "—are not a rhetorical expression, but a specific revealed truth (cf.* 1 Co *6.15) from which a clear program for life is deduced. Handicaps, all forms of handicaps, never undermine the dignity of the person or his right to the best quality of life, as demonstrated by, among other things, the results obtained in sports activities themselves—in rightly opening themselves to the disabled, they have given them reasons for legitimate and exemplary pride and have thus become a celebration of authentic values of physical and spiritual recovery. The recent Olympic Games in Barcelona provided new and splendid proof of this.*

" You are the members of the Body of Christ ": the Body of the Risen One! This is the true foundation for an indestructible dignity! A dignity withstanding even the setback of death. It is, in fact, said, " This corruptible body of ours will be robed in incorruptibility, this mortal body of ours will be robed in immortality " (cf. 1 Co *15.52).*

Distinguished Ladies and Gentlemen, in the luminous perspective which the word of God opens before the eyes of faith, I address to each one of you a warm invitation to persevere in dedication to the noble cause of the advancement of the disabled. May Our Blessed Lady, Star of our earthly pilgrimage, accompany you and arouse in the hearts of all men sentiments of fraternal sharing, so that from the meeting between suffering and love there will issue forth and affirm itself in the world the value of solidarity, inextinguishable source of justice and charity.

May God make the orientations and purposes brought to maturity over the course of these days fruitful with his grace, and upon all of you present here, along with those who have taken part in the sessions of your Assembly, may the Apostolic Blessing descend, a promise of renewed commitment in the service of the Gospel of hope.





Introductory Remarks

A greeting and an expression of thanks to the eminent scientists, researchers, and scholars who will offer their knowledge and experience as a contribution to these days of reflection and study.

A greeting and expression of the most keenly-felt gratitude to all those who are here present for the faith they have in this important annual meeting of ours. The Pontifical Council for Pastoral Assistance to Health Care Workers considers these meetings a moment of great relevance in its activity of ecclesial service in the world of health policy and care.

This Seventh International Conference, like its predecessors, deals with a subject of great contemporary relevance and a whole host of implications.

Congenital or caused disability afflicts half a billion people, two thirds of whom live in developing countries. If we add a qualitative perspective to this quantitative assessment, the picture becomes even more dramatic. It is obvious that the number and character of handicaps is greatly influenced by the unequal distribution of resources, the continuing presence of conditions of life which are offensive to human dignity, unacceptable models of development, and by unpreparedness and indifference in tackling a very serious problem which, for reasons which have been outlined, also constitutes a threat to future generations.

This conference of ours, essentially, has two fundamental aims: to illuminate the condition of disabled people in today's society and to reaffirm the direct and supportive commitment of the Church to those who work in the service of disabled people. The goal is to cancel all forms of marginalization from their existence and to work together in all fields and at all relevant levels to achieve improved health care for disabled people, to attain their social reintegration, and to promote a positive human and spiritual appreciation and recognition of their capabilities and their potential.

Science and technology are far ahead of general civilization in the field of care and support for the disabled, even if they are a component part of it.

Too many of our brothers and sisters who are afflicted by disability are unable to benefit from the conquests of science and technology. Furthermore, where these conquests are put into practice and utilized there is often a lack of necessary human and spiritual support—things which the disabled person, more than any other form of help, perceives as being urgent and necessary.

Every time that I see, with emotion and pride, these brothers and sisters of ours achieve extraordinary results and thus make themselves bearers of a message of hope which is often unknown to those who do not suffer from a disability, I think of the enormous responsibility borne by each one of us, by public authorities, by charitable and humanitarian institutions, and by all those who are called upon to work for the care, treatment, support, prevention, and positive appreciation of these brothers and sisters.

The contribution, therefore, that this conference wants to offer is not only of a pastoral and scientific character. It also has the goal of shaking consciences. I think it is very significant that this conference of the disabled takes place on the eve of the celebration of the international day of handicapped people established by the United Nations and the World Day of the Sick called for by the Holy Father.

Amongst those who bear the burden of special physical suffering, a majority is made up of disabled people. They must not and cannot feel alone. This is because, like every other human being, they are the members of Christ. And Christ, in taking on the form of suffering human nature, secured the redemption of the world.

FIORENZO Cardinal ANGELINI
President of the Pontifical Council for Pastoral Assistance to Health Care Workers

OPENING ADDRESS BY ANDRZEJ MARIA Cardinal DESKUR

The Disabled Person As an Instrument of Salvation for Human Society

It was with no little emotion that I received the news that the pontifical office which deals with questions and matters relating to pastoral assistance to health care workers in the modern world was going to organize an international conference on handicapped people in the light of their being members of the body of Christ and of society. The title itself of the conference already captures the heart of a complicated and intricate subject which will be discussed by many leading lights of the scientific world and especially by exponents of those disciplines which are very relevant to the whole question.

Cardinal Angelini, our revered president, in a display of his well-known sensitivity towards all those human and religious questions which concern modern man and medicine, has wanted to entrust these conferences not only to leading personages of the world of science—whom we will listen to with great care and attention—but also to an ecclesiastical figure who can present certain reflections of a theological or even personal kind on the question of suffering and the meaning of suffering in the Body of Christ—the Church.

I believe, therefore, that those who are gathered here expect from me those reflections of a theological kind which are captured by St. Paul in his letter to the Colossians: " in this mortal frame of mine, I help to pay off the debt which the afflictions of Christ leave still to be paid, for the sake of his body, the Church " (Cf. *Cl* 1:24.).

The fact that all the members of the mystical body of Christ—following the example of the Most Holy Virgin and in unity with our Lord—are called upon to take part in the co-redemption of the world, is an uncontested truth of the Christian faith. Obviously enough, this does not mean that our Father in heaven welcomes the pain of his children. On the contrary, we know that Jesus always sought to reduce the pain and the afflictions of those he encountered with miracles and words of comfort and suppport.

During her history the Church has done exactly the same through her charitable and hospital activity, and has created for this purpose specific institutions for men and women.

Our Father in heaven welcomes only the loving obedience of his children in their acceptance of his will, even at the price of Gethsemene and Calvary: " Was it not to be expected that the Christ should undergo these sufferings, and so enter into his glory? " (cf. *Lk* 24:26-7).

When I re-read today the accounts of those who were incarcerated in the Stalinist Gulag Archipelago or in the Nazi concentration camps, I think that I have a better understanding of the feeling of the handicapped person who is limited in his freedom and in his personal development by the affliction which besets his body. I might point out in passing that in addition to the experience of this wheelchair I have also undergone, even if for a short while, the experience of Stalin's prisons. In reality, man is in the world and exists for the world and therefore cannot shut himself up within his own feelings and renounce personal sacrifice. He must turn himself to the whole of creation, which is in process through his own life. In line with this idea of a providential divine plan, the handicapped person must be constantly invited to live at the same time within the context of human history and in the divine truth which projects him into eternity.

From this springs the need the handicapped person has for a strong element of contemplative experience which will allow him to understand the importance of the present moment in his life. This is so even if he is afflicted by suffering and held in by the tyranny of his condition. He must understand its true value within the context of human history and the divine plan of salvation set in motion for the benefit of humanity. This is a plan which—to once again use a Gospel

image—comes to fruition through the sufferings of a spiritual birth which will have as its culmination the joy of seeing a man born again in the light of redemption.

" There is no imprisoning the word of God " (*2 Tm* 2:10). The disabled person, if he allows himself to be shaped and molded by the Spirit of God, can and must make himself an instrument of salvation for human society.

Before us we have the infinitely perfect model of Christ nailed on the cross on Golgotha that Friday two thousand years ago. It was at that moment, indeed, that He himself—made a " disabled person " by the madness of cruel men—brought to fulfillment the plan of the Father for the redemption of all mankind.

And it was in that situation of physical incapacity that Christ performed the ultimate act of oblational love and of total giving of what belonged to him so that mankind could rediscover its friendship with the Father. He also gave us the merciful Mother, and he did this when he proclaimed her Mother of all living beings.

I do not want to present this assembly with a mystical reflection at the start of this most important conference—a conference which seeks to draw the attention of the world to an aspect of the social fabric which is so widespread and which aims to study, in interdisciplinary fashion, ways and means of breaking down the barriers which still separate the disabled person from the rest of the community.

In taking into account the nature of existing realities, I believe that society should urgently be made aware of the fact that the isolation and loneliness which surround the disabled person suffocate within him those gifts of mind and spirit which he receives from on high.

Experience demonstrates that wherever the community comes into spiritual, moral, or physical contact with somebody who has difficulty in communicating with the outside world by the usual methods, the disabled person finds that he can perform great works of human undertaking. Thank God, in the world today there is a vast presence of generous and involved people who devote themselves to this service.

Solidarity and participation find their model to follow in the example of Golgotha.

The presence of the Mother of the Cross was made richer by the presence of other people who were not bound to Him by ties of blood. Various women who had challenged the hate and the derision of those perpetuating the crucifixion were at the foot of the cross. They were bringing the proof of their own love and their own sense of solidarity. This presence was the expression of a service of participation with the disabled but divine being. He did not feel alone, abandoned by all, or not understood by anybody.

There was only one man—John. He overcame all feelings of fear and human regard, and looked all possible negative outcomes in the eye. John was next to the Mother and to the crucified Christ. In this way he expressed his wish to share the fate of his Master and his Friend.

It is not always, and not only, selfishness which causes the disabled person to be abandoned to himself. Often, indeed very often, it is the result of the blindness and stubbornness of a world which exhalts super-efficiency to levels almost of paroxysm and sings to the triumph of the healthy and beautiful body. In doing all this, the world erects a barrier of human disrespect and even of irony which distances whoever wants to draw near to the disabled person.

Nonetheless, the world can be made richer and become truly human in uniting its existence with us, with disabled and handicapped people.

John Paul II, who is a great expert in the area of suffering and has experienced it from early childhood, gave breath to words in the apostolic letter *Salvifici Doloris* (no. 30) which should become a code for behavior. He says, in fact, that " suffering is present in the world so as to give rise to works of love towards one's

neighbor, to transform the whole of human civilization into a ' civilization of love. "

The wonderful reality of this international assembly which is gathered here in a fraternal spirit and is composed of disabled people, relatives, voluntary workers, scientists, men of government, and men of the Church, has a clear aim: to study and to assess, together, what should be done so that things do not remain as they were. This conference, above all else, asks each one of us what we are prepared to do to help and serve others.

Clearly, we do not expect the miracle of the disappearance of disability from the face of the earth. But we can certainly ask for a miracle and hope for one. It will be a miracle when all of us here go back to our daily activities and become exponents and tellers of the Good News: that love, mutual understanding, sharing, and generous solidarity, can overcome any barrier. Let us proclaim to everybody that together, and united, we can build that civilization of love which is the only way by which we can save our world from this mad headlong rush towards self-destruction.

I am a priest, a bishop, and a Cardinal who carries within his very flesh that message of the disabled person. And you, my brothers and sisters present in this great hall, and hundreds of millions of disabled people all around the world, do the same. But in the words of the Apostle Paul I can repeat with joy and hope the private sentences that he wrote to the faithful of the Church of Corinth:

" For ourselves, we are being hampered everywhere, yet still have room to breathe, are hard put to it, but never at a loss; persecution does not leave us unbefriended, nor crushing blows destroy us; *we carry about continually in our bodies the dying state of Jesus, so that the living power of Jesus may be manifested in our bodies, too.* Alive as we are, we are always being given up to death for Jesus' sake, so that the living power of Jesus may be manifested in this mortal nature of ours..., and knowing that he who raised Jesus from the dead will raise us, too " (*2 Co* 4:8-11)

We put ourselves in the hands of Her whom the Council Fathers called the " Mother of the Living " (*Lumen Gentium,* 56) and who, at a time decided by God " was to behold her Son in his glory at the right hand of the Father, She who had seen Him on the cross, She who was spared pain when She brought him into the light, She who was pierced by the sword of pain when She saw Him die. " [1]

In a few words, I would like our conference to help the handicapped by making them fully aware of the task of renewal that they are called upon to perform in this world—a world which is afflicted by so much darkness because of its disobedience to the Creator and because of a lack of love. A love which, in the words of Dante, " makes the stars move in their orbit, " and which could also change the world into a better place by being reborn through the beds of pain and suffering. This is a sublime task which ideologies and politicians hardly ever manage to bring to fruition.

ANDRZEJ MARIA Cardinal DESKUR
Emeritus President
of the Pontifical Council
for Social Communications

[1] Pius XII, Apostolic Constitution, *Munificentissimus Deus*, *AAS* 42 (1950), 760-762.

H.M. QUEEN SYLVIA OF SWEDEN

The Disabled: Sharing in the Fellowship of Society and the Church

The theme of this international conference is " your members are the body of Christ: persons with disabilities in society. " The very important question we are here to discuss is thus how we—handicapped or nonhandicapped—are to be able to share in the fellowship of society and the church.

We can learn a great deal from the people who have sufferend functional impairments of different kinds. In their struggle to overcome the difficulties they meet as a result of their limitations and other people's attitudes, they often display qualities that one wishes were more generally prevalent.

Let me tell you what happened in the north of Sweden a few years ago: five severely disabled young people decided, after having studied together at a county college for several years, that they wanted to try living together in a warden-controlled dwelling. The local authority supported them by building a suitable house and promised to provide the personal assistance the youngsters needed. During discussions with the young people about their expectations and possibilities, they were asked what each of them expected to contribute to the collective. One could cook, another could drive, another worked in a sheltered workshop and so on. When asked what Martin, who was the most severely disabled of them all, could contribute, the others answered: " He will be one of us. " The handicapped young people have thereby given us an answer to the question that is the theme of today's conference.

I have found another answer in the fellowship that exists in the handicapped sports movement. For several decades I have had the privilege of following handicapped youngsters' struggle against their physical and mental problems as expressed in their participation in sports.

Through sports, they have found a way to master their fate during play, training and resolute pursuit of their goal in fellowship with others. With increasing admiration, I have watched them develop a single-mindedness, comradeship and fighting spirit that is worthy of all respect. Paul's words to the Corinthians spring to mind: " Do you not know that in a race all the runners run, but only one gets the prize? Run in such a way as to get the prize. " The seriousness with which handicapped athletes compete may serve as an example to us in our efforts to achieve our objectives. Many of the competitors admittedly dream of winning the victor's wreath or medal, and sports are a way for them to master their physical impairments, but when one sees their comradeship and

endeavor, one understands that there are other values as well.

Perhaps it is time we all appreciated the importance of people's efforts not being judged in relation to the number of medals or financial success but what they strive to make of their lives, regardless of how fortune has treated them. Handicapped sports have become a movement that is growing ever stronger. In 1985 the King and I took the initiative, through the Royal Wedding Fund, for the publication of a book —Go for It!—, in which handicapped athletes described their sports, their experiences, and their feelings. Their stories have attracted a lot of interest and the book has been published in German, English and Spanish versions as well as the Swedish edition. This year we have had the olympic as well as the paraolympic games, the objective of which is to foster fellowship and comradeship. Owing to the participants' different circumstances—sex, weight, sail size, etc—the contestants are divided into different classes. I look forward to the day when people with disabilities can also share in fellowship, as one of us.

People with disabilities are in greater need than others of medical, social, and other support from society, the church and private individuals. And it is not only our duty but also our privilege to work towards a community which functions for everybody. The church is, as we heard from Cardinal Bevilacqua, setting up an example here by adapting its churches, schools, and other premises to the needs people with disabilities have so that they can take part in fellowship with us.

Education, technical aids, and personal assistance can make life easier for the handicapped. Support for their families, particularly families with handicapped children, is also important, if we are serious about wanting to help the handicapped and their families to participate in our activities. In order to achieve this objective it may sometimes be necessary to introduce legislation which ensures the individual's rights. In Sweden there is a proposal to create a special so-called *ombudsman* who would generally support and represent the handicapped with advice and information and who would help them in their dealings with local and government authorities.

It is also important that we all play our part in helping to *prevent* disabilities. One of their major causes is malnutrition. We can all help to prevent hunger in different countries. Above all, we must do everything possible to ensure that pregnant women, children, and nursing mothers receive an adequate diet.

In all our efforts to help people with disabilities, it is important that we listen to them, rely on their personal abilities and show them that we believe they are able to take responsibility for their own lives. They must not be allowed to become the passive objects of our efforts. We must enter into relationships so that we can meet as equals, one person with another.

When Jesus walked this earth he made no distinction among people because of their bodily defects, functional abilities, or capacity. To him, physical health and the spiritual dimension formed a single entity—divine creation. It is self-evident to us who call ourselves Christians to be prepared as implements of God's love to meet the handicapped in the right way and embrace them in our fellowship. It is our duty to contribute to restoration of the lost wholeness by preventive measures at home and at work, rehabilitation in the health and social welfare sector, education, measures to influence public attitudes and actions as well as in our personal encounters.

Meeting a handicapped person means meeting a fellow human being with special problems and questions. Some of the problems and questions can be solved with the help of specialists' knowledge and experience. We often lack answers to the existential questions that always arise in connection with crises and adverse events in a person's life, but it is still important that we have the courage to face them. In their meetings with other individuals, those afflicted can sometimes find an answer which helps them to carry on living and pass on the divine love that has been given to us.

I will conclude by describing how a young mother found an answer to the question of God's meaning and move on to the question of his purpose. She said in all humility: God has so many children. He is particularly concerned about some of them—those who need special loving care, the handicapped children. We have been given one of these children to look after. In entrusting this task to us, God has shown great faith in us.

H M. Queen SYLVIA
of Sweden

MOUNA HRAOUI

Disabled Persons in Society

As I stand here before you, I cannot help but tell you how much in awe I am at the wealth of science that surrounds me. Being no scientist, I shall ask you to bear with me as I speak in layman's language. But first I would like to thank you for inviting me to participate in the Seventh International Conference organized by the Pontifical Council for Pastoral Assistance to Health Care workers and devoted to Disabled Persons in Society.

I take this opportunity to express our deepest gratitude to His Holiness Pope John Paul II and to the Vatican for their continuous support for the peace and reconstruction process in Lebanon; a process which has finally gained momentum in the aftermath of the war.

I come from a country devastated by sixteen years of strife; a country determined, nevertheless, to engage in a reconstruction effort which is not only physical and economic in nature, but basically human. Indeed, Lebanon has lost during the war its most important economic resource, human capital, since many Lebanese have fled the country in search of a better place; an exodus which has caused a huge brain drain and is being severely felt both physically and psychologically now that reconstruction is underway. Furthermore, the disabled constitute today a significant part of the Lebanese society. That is why the topic of this conference is of utmost relevance and concern to us.

My talk today will focus on the disabled in Lebanon, who fall into four categories under Lebanese Law:

a) the physically disabled;

b) the blind, the deaf, and the mute;

c) the mentally disabled, and

d) those suffering from chronic diseases such as diabetes and thalassemia that might ultimately incapacitate them, if not properly treated.

The problems of the disabled in Lebanon are common to all countries. Underdeveloped countries considered them to be God's will and a sort of punishment to their parents. Advanced countries have developed adequate social and scientific programs to help the disabled cope with their problem and live within family and society.

Lebanon, like most developing countries, and particularly as a result of the war, suffers from a lack of adequate statistics. Studies on the disabled have been carried out by many social institutions, but have not been comprehensive. The first reliable survey on the subject was undertaken under governmental supervision in 1981—a year declared by the United Nations as the year of the disabled.

The objectives of this first wide survey were:

1) to assess the magnitude of the problem of the disabled in Lebanon and its breakdown by social and economic group, as well as age, sex, and region;

2) to determine the causes of physical and mental disabilities;

3) to examine ways and means of improving the rehabilitation of the disabled and widening the scope of the services rendered to them.

According to this survey there were in Lebanon in 1982, 43,896 disabled persons, in addition to those whose age was above 65 and those suffering from chronic diseases.

Although no official surveys have been conducted since, it is estimated that the number of the disabled has reached 109,083 in 1992, 3% of the total population, as compared to 1.08% in 1982. A significant part of this increase is obviously due to the war. (Disabled above 65

and those suffering from chronic diseases are included.)

Caring for the disabled in my country goes back to 1868 when an American lady, Mrs Thomson, opened the first school for the blind in the Middle East. Since then the private sector has been active in the social field, but help has somehow lagged behind because of the social taboos associated with disablement.

In the 1950's, two important centers for the disabled were established: one for the blind, the deaf, and the mute under the patronage of the late Mrs. Zalfa Chamoun, wife of our late President, Mr. Camille Chamoun; and another by the late Monsignor Cortbawi, for the physically disabled. The Cortbawi Center has unfortunately been completely destroyed by the war and although its location has been changed, it has not been fully reequipped because of lack of funds.

After modest beginnings, the public sector assumed a larger role in the social field when in 1959 it established the Office of Social Development, which started to look intensively after the disabled.

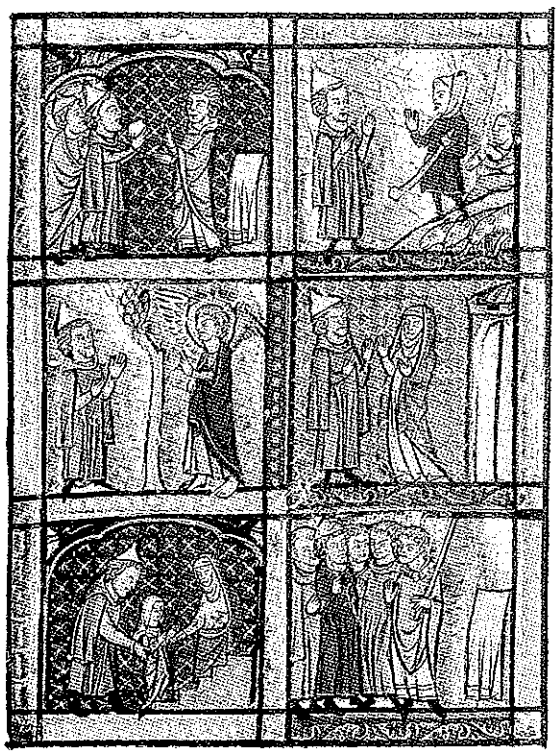
As a result of the war, the number of the disabled increased drastically and, to cope with the problem, a special section was created in this office in 1977. In 1982 the office of Social Development became the General Directorate of Social Affairs, including the special section for the disabled, which was specifically established to look after their general welfare and rehabilitation.

The private sector also witnessed a quantitative and qualitative expansion. In Lebanon, there are presently 61 specialized institutions taking care of the disabled. The government supports them by paying selected institutions a daily cost per person. This year the number benefitting from this arrangement is 2,458 children, of whom 658 are receiving technical training. These funds are distributed among 24 institutions chosen by the Directorate General's Specialized Care Section for the disabled. The annual governmental support received by these institutions amounts to L.L. 700 million, equivalent to U.S. $ 400,000, and is expected to reach L.L. 2.1 billion, equivalent to U.S. $ 1,100,000, as a result of an increase in allocated daily subsidy.

However, the Specialized Care Center run by the section for the disabled, like many other institutions in Lebanon, was not spared by the war and lost all of its technical equipment; equipment which has not yet been replaced because of financial constraints. Nevertheless, it is still operating, although with limited resources.

In addition to the Directorate General of Social Affairs, there are other public institutions that take care of the disabled: the Directorate General of Health, which provides treatment to the disabled in its hospitals, and the National Employment Institute, which secures training in specialized institutions for disabled rehabilitation, helping them find suitable jobs.

The tragic Lebanese events led the governmental and nongovernmental institutions of this country to increase their activities in the social field. In fact, they it generated genuine concern for the disabled on the part of international social institutions. And a large number of these



organizations have helped Lebanese private institutions by providing them with technical equipment and training sessions for social workers. The International Red Cross is such an organization. It helped three institutions set up three factories for artificial limbs and trained some of their staff to work under their supervision. Another is The World Rehabilitation Fund, which organized in 1985 meetings and conferences in Cyprus to which officials of the Ministry of Health and Social Affairs, as well as members of the Lebanese University and representatives of non governmental institutions from all over Lebanon were invited. The purpose of these meetings and conferences was two-fold: (a)

to coordinate che activities of the public and private sectors and those of institutions that take care of the disabled; a coordination that could not take place in Lebanon because of the prevailing conditions; (b) to examine the possibility of providing assistance to these institutions and organizing programs to help the disabled in society.

In 1989, the World Rehabilitation Fund started implementing in some selected social centers, a special program known as " The Community-Based Rehabilitation System, " the aim of which is the provision of the largest possible amount of services to the disabled within their society, their environment and their

homes. In order to fulfill these services, there are three topics to be discussed:

1. Treating the disabled on an individual basis

The social worker through daily visits and observations of the disabled's condition and environment will determine an appropriate solution to thier problem.

2. Treating the disabled through society

Awareness of the society through visits to social and health institutions, together with the cooperation of local authorities, to resolve vital matters related to the disabled.

3. Working with disabled groups

Working closely with the disabled and their families will help find mutual solutions to their needs and rights.

After three years of field work, it became apparent to the Fund and to the Directorate General of Social Affairs that there was an urgent need for training programs that would adequately prepare social workers to cope with the disabled. For this purpose, a commission from the Lebanese University, the World Rehabilitation Fund, and the Directorate General of Social Affairs was formed. This Commission has, during 1992, organized four training sessions, The last is scheduled for December 1992 and will deal with the professional training of the disabled.

To accomplish these objectives, this program requires ample financial means and constant training of social workers all over Lebanon.

Besides the above-mentioned organizations, the Lebanese Red Cross helps the disabled by providing them with some of the medical equipment which they need, such as wheelchairs, crutches, and walkers, some of which are produced in its own workshops, and also by making the necessary adjustments in their homes in order to help them be more functional.

The war that ravaged Lebanon led to such destruction, displacement, and misery that no one could remain indifferent to it. In my capacity and given my personal interest in social work and humanitarian relief, I became deeply involved in providing emergency humanitarian assistance to the needy and founded the Lebanese Permanent Committee for Coordination (CLPC) with the help and support of devoted ladies who chose to cooperate with me. Our immediate concern was to provide emergency help whenever and wherever needed in Lebanon. Gradually, however, the CLPC extended its field of action by contributing to the organizations. In fact, the disabled are of prime concern to us. For this reason, the CLPC has decided to focus its efforts now—after three years of tireless and dedicated relief and social work—on a particular category of potentially disabled persons, namely children suffering from diabetes and thalassemia.

For this purpose, we have decided to build a center—the Chronic Care Center—the aim of which is to allow disabled children to lead a normal life and to spare them the drastic consequences that could result from lack of proper treatment. We have already laid the cornerstone of this Center and are in the process of raising the needed funds to build it and

provide it with the necessary equipment. And here may I express my sincere thanks and appreciation to all private institutions and individuals who have given us their unfailing and invaluable support during these years.

As you can see, our plans for the disabled are quite ambitious, but, unfortunately, our means are limited. But despite this difficulty, we are determined to improve our lot. That is not an easy task. It will entail the adoption of a series of measures, the most important of which are:

1) The accurate updating of the statistical survey undertaken in 1982 in order to get a precise picture of the disabled as far as their number, categories, and needs are concerned.

2) The renovation and reequipment of all the specialized training centers for the disabled to facilitate their smooth integration in to society.

3) Spreading centers for Community-Based Rehabilitation Systems all over Lebanon.

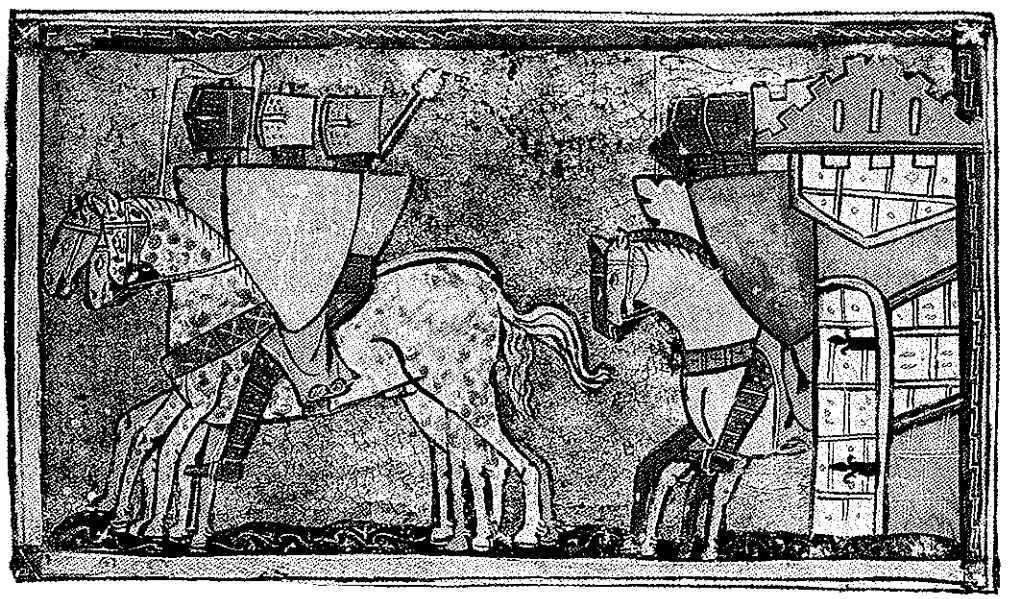
4) The setting up of special sheltered workshops for those adults who cannot cope on their own, to enable them to face life and society with dignity.

5) The need to involve the public in an effort to develop more social concern on their part.

The disabled are full-fledged citizens with undeniable rights. Let us work together to give them these rights. Equitable and sustainable growth in my country will never be achieved unless economic reconstruction is coupled with social reconstruction. Help Lebanon, which was one of the founding members of the United Nations and a contributor to the Declaration of Human Rights. Help it improve and develop its human capital, rebuild its social network, and reintegrate its place in the civilized world. I am confident that my appeal today will not remain unheard.

Thank you.

Mrs. MOUNA HRAOUI
The First Lady of Lebanon



SUSANNA AGNELLI

Disabled Children Are Also the Future of Society

The title of my paper is an act of faith. As a Christian, in this place and at the end of an international conference on the subject " Your Members are the Body of Christ: Persons with Disabilities, " I share with all believers the theology of the Mystical Body. I further share the spirit of human solidarity which moves all those, in both the voluntary sphere and institutions, who find it simply intolerable to halt at drawing attention to the existence of disabled people and not act to change things. We do this with a keen awareness of the presence of very great limitations—very much due, as the Nobel Prize winner, Professor Dulbecco, has pointed out, to our continuing narrow range of knowledge in the realm of genetics—but also with great hope in the possibility that these limitations will be pushed ever further back.

His Eminence Cardinal Angelini, when he introduced this conference, spoke about the need to shake consciences and to change mentalities. This is also the ambition of the Italian Union for the Fight Against Muscular Dystrophy (UILDM). UILDM seeks to achieve its aims through an attempt at social and material support for handicapped people and through more dramatic initiatives such as the Telethon. This is a television marathon modelled on American and French precedents which aims at collecting funds for scientific research. I am involved in this television initiative because of my membership on the promotional committee, and this is the reason for my presence here today amongst you. A mass media operation such as this combines the weighty task of collecting large sums which are essential to such research with the no less important task of making people more aware of, and concerned with, the condition and difficulties of disabled people.

In the case of muscular dystrophy—the subject of the activities of the Telethon promotional committee—one is dealing with disabled people who keep their mental faculties and lucidity fully intact. But at the same time they have to cope with a thousand obstacles. These obstacles are both physical and social: the attitudes of others; architectural barriers and the difficulties provoked by a body which no longer responds to the will and only functions with difficulty in the automatic sphere, such as with breathing.

Historically, there has been a great advance since ancient times, when disabled people were simply done away with. In a less distant epoch they were only separated or hidden. Nowadays, the previously " private " handicap has become " social. " Today we live with handicaps, but it is still a passive process. Too much distance and too much estrangement separate the disabled from the so-called normal. To affirm that " handicapped children, too, are the future of society " is truly an act of faith, of hope, and of charity.

With regard to schools—institutions of primary relevance when one talks of children—even when (although not always and not everywhere) the handicap is taken into account, the disabled person is much more " protected " than integrated. This does not arise because of bad will but because of objective difficulties which must be dealt with in an area which already presents a host of difficulties: how to reconcile the integration and the learning of the disabled person with a system which is often lacking in the right structures and frequently deaf at a bureaucratic level.

Research undertaken on behalf of the Telethon by a specialized organization has revealed that both as regards activists in the field and amongst the general public there is a sense of powerlessness and passiveness which is often hidden behind declarations of self-exculpation and throwing responsibility onto public authorities. This research aimed at finding out about general social attitudes and stances towards disabled people within the context of the television campaign to make people more aware and

concerned with the whole question of muscular dystrophy. The need for solidarity, which has been rendered stronger by television, seems to find its most rational reply in this attributing responsibility to who ever knows the right people, to who ever might be able to do something, or to whoever should do something ...or in admirable, indispensable, but not exhaustive financial aid.

All of us who are working with Telethon, while we try to do our best to involve as many people as possible in the whole project—in an economic sense as well—feel the need to impart more cultural and theological substance to an enterprise of fund-gathering which clearly has the merit of representing a way of leaving powerlessness and surrender behind and of turning scientific research into a strategic answer and a rich source of hope.

" Shake consciences, change mentalities, " Cardinal Angelini said. Speaking in this place, I am led to say that we need an authentic conversion in the *metanoia* sense, a change in mentality. To believe with us that a disabled person is a part of the future of society means an ability to found a relationship with him which tolerates, bears, and overcomes that measure of death which he brings with him, and which leads to a joint challenge to the difficulties of life.

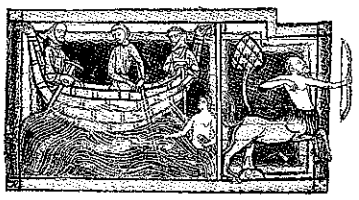
In the Telethon promotion campaign there is the image of a wheelchair followed by a bicycle with the slogan " Let's help those who suffer from muscular dystrophy to change the channel. " This seems to me to be a practical act of faith, a simple way of asserting their value and the social good that they themselves represent, and not only because of the positive feelings that they provoke in us and which generate solidarity. This seems to me to be an indispensable step to allow them to believe in themselves more and to make a greater effort to be active within society. Some of them are already doing this. Certainly not at the level of Professor Hawking, the most well-known case of muscular dystrophy and one of the leading world authorities on astrophysics, despite the fact that he is confined to a wheelchair and forced to communicate through a computer. But there are people who suffer from this affliction who teach—beginning with the president of UILDM—and who are lawyers or engage in other professions.

The future seems well-disposed to wards the achievement of integration into the world of work: physical strength no longer occupies the central place that it once held in the workplace. The computer, with its manifold applications and uses, allows forms of work and professional activity which would have been unthinkable at one point. There is much talk of work at home, even for " normal " people, if only to reduce urban traffic levels. In the future cabled city a different and more active presence of disabled people seems possible.

In a city which still belongs to the future and which is being prepared by the technological revolution—but also by a cultural revolution if we really want to improve the current state of affairs. What one is speaking about here is the creation of a new impulse and direction in the consciences of men.

In my understanding of faith, the Holy Spirit is the *Dynamis*, the force, the strength, and the dynamism of God. I hope that He will animate and sustain our task and our faith.

SUSANNA AGNELLI
President of the Fund-Raising Committee of the Italian Union for the Fight Against Muscular Dystrophy



ANTHONY Cardinal BEVILACQUA

Persons with Disabilities: A Living and Vital Part of the Church Community

" Now you together are Christ's Body; but each of you is a different part of it " (*1 Co* 12: 27).

In my own training and in my years as a young priest, I had very little experience with persons with disabilities. I vividly remember one encounter a few months after I was ordained when a young mother asked me to bless her and her two young daughters. When I bent down to ask their names, the little girls smiled beautiful smiles but did not answer. Upon learning that they were both deaf, I found myself confused, almost angry. Why had this mother asked for my blessing? What could I do? I did not have the power to make them hear as Jesus did when He put his fingers into the ears of the deaf man. Then I became aware that this woman was not asking for a miracle but for what any mother would ask for her children—God's power and grace in their lives and in her own to be the mother they needed.

As with my experience with these deaf children, many of us typically feel a sense of powerlessness and helplessness when confronted by a child without sight, a stroke patient unable to speak, a young man whose sole body movement is a painful turning of his head. Persons with disabilities make us feel uncomfortable because they also remind us of our own vulnerability; the inescapable reality that for all of us life ultimately leads to death. Our disabled brothers and sisters are prophets in our midst giving them lie to what others have termed the " cult of perfection, " a false religion whose gods of perpetual youth and beauty are worshipped without question, particularly in the nations of the First World.

We need to be aware not only of the presence and needs of persons with disabilities in our midst but also of our own attitudes and feelings. Often we find it easier to isolate and ignore those whose experiences confront the myth that we have control over our lives and our destiny. Parents of a mentally ill son speak with understandable sadness about parish priests who never inquired about their well-being or that of their son. This couple has channeled that bitterness into advocacy and education to overcome the stigma of shame that still attaches to persons with mental illness in their families.

Even those of us who have overcome our fear and ignorance to become professionally, pastorally, or personally involved in the lives of persons with disabilities often distance ourselves by categorizing, objectifying, or confining to their disability the persons we seek to serve rather than, as my brother bishops phrased it in their 1978 *Pastoral Statement on People with Disabilities*, " working for a deeper understanding of both the pain and potential of our neighbors....whom disability may set apart. " Medical researchers and health care workers treat persons with physically disabling conditions as medical problems to be diagnosed and cured. Human service administrators view the struggles of persons with mental illness to reintegrate into community settings as faceless caseloads whose well-being is largely a matter of adherence to regulations and access to public funds. Church catechists perpetuate the myth of the " holy innocence " of young adults with mental disability by resorting to the use of children's materials rather than by working to adapt and simplify more age-appropriate curriculum. A blind woman who is married, a mother, a computer instructor with a Master's degree, and a lector in one of our parishes states that for her " the greatest suffering is not in my disability but in the attitudes of others " who seek to define her by and confine her to her blindness.

In valuing persons with disabilities as worthy of respect and dignity, we need look no further than the example of Jesus himself, who sought the company of those whom the society of his own day often ignored and rejected. His healing of their bodies was symbolic of the spiritual

healing of which all of us are in need. The gospels tell us that when the blind beggar Bartimaeus approached, Jesus did not presume what his needs were but accorded him the respect of asking, " What do you want me to do for you? " On another occasion, Jesus felt his healing power respond to the faith-filled touch of the woman with a hemorrhage, anonymous in the pressing crowd. He insisted on having her come forward, not to scold her as she first suspected but to affirm her faith and courage and to put a human face on the outpouring of divine power. Here and throughout his public ministry, Jesus knew that the people he touched were more than their disability. He was exquisitely aware of the image of God reflected in each of them.

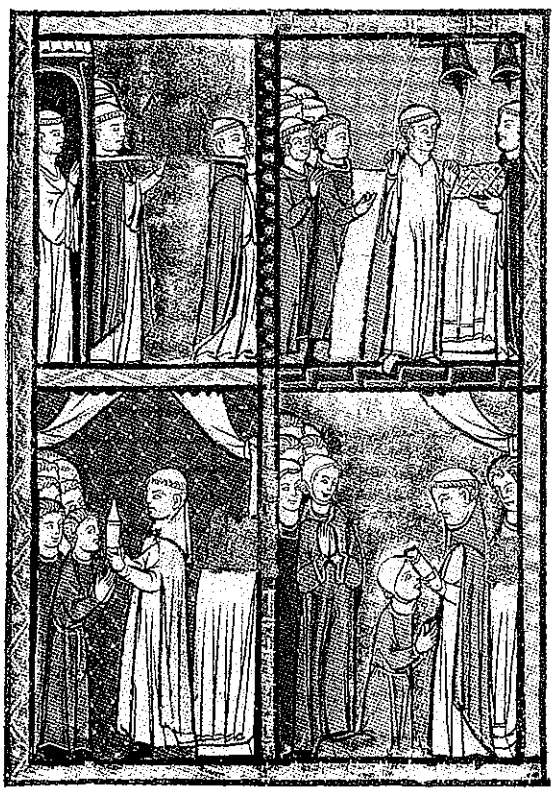
" ...The parts are many but the body is one. The eye cannot say to the hand, 'I do not need you,' nor can the head say to the feet 'I do not need you.' What is more, it is precisely the parts of the body that seem to be the weakest which are the indispensable ones... " (*1 Co* 12:18-22).

First we must become aware of our attitudes toward our disabled brothers and sisters since attitude is often the first barrier they encounter and the one most resistant to change and removal. But our attitudinal " metanoia " must be accompanied by actions which promote the inclusion of persons with disabilities in the life of our Christian communities. Evangelization presumes a welcoming community—one whose door is always open. Often enough our church doors may indeed be open, but a person using a wheelchair faces a mountain of steps to get to that open door!

A recently enacted law in the United States, called the Americans with Disabilities Act, requires public and commercial entities to make their facilities accessible to persons with disabilities. The ADA has been hailed as perhaps the most far-reaching legislation ever passed guaranteeing civil rights to an estimated 43 million disabled Americans. By virtue of their baptism into the Body of Christ, our disabled members already possess the right to participate fully in the liturgical and sacramental life of our parishes. As one visually and hearing impaired woman who participates in the parish choir by interpreting the songs in American Sign Language put it so well: " We hunger for the Word and want to hear it like anyone else. We who are disabled have a right to the truth and to be members of the Body of Christ with equal privilege to share His table. "

It is foolhardy to pretend that architectural accommodations, assistive listening devices, large print and brailled materials will not require the expenditure of often scarce funds by parish communities already struggling with high maintenance costs of old, deteriorating buildings and the more pressing demands of social outreach to people in need. To quote again from the American Bishops' Pastoral Statement: " Mere cost must never be the exclusive consideration, however, since the provision of free access to religious functions for all interested people is a pastoral duty. " Like the friends of the paralytic, who gained access for him to the healing touch of the Lord by lowering him down through the roof, we must be persistent and creative in ensuring for disabled members the opportunity to encounter the Lord in our midst.

Nor should any of us who are temporarily



able-bodied ever underestimate the intensity with which our disabled members desire to join us. Not long ago a woman who uses a wheelchair after becoming paralyzed as a result of a car crash a dozen years ago was asked to evaluate recently completed accessibility features of our Cathedral in preparation for a special Mass for persons with disabilities and their families. Two diocesan staff accompanying her were busy making notes of hich doors would need to be propped open and how the traffic flow of more than seventy wheelchairs might be managed when she paused at the top of the center aisle in front of the high altar and requested a few moments alone to pray. When she rejoined the

others, there were tears in her eyes as she confided that, prior to her accident, she and her husband had celebrated twenty—five years of marriage together with couples from all over the Archdiocese at the Silver Anniversary Mass at the Cathedral but that she had assumed she would never be able to return for future celebrations.

Equally important as making our churches accessible is adapting our programs and activities to allow the full participation of persons with disabilities. At our annual retreat for deaf women, one of the retreatants spoke of the pain she experienced as a child a half century ago when she was denied the reception of her First

Holy Communion because she was deaf. Fortunately, a young parish priest sensed both her hurt and her longing and prepared her himself with individual instructions and then vouched for her readiness. As so deeply felt by this woman, the wounds of the past can only be healed by our continuing efforts at inclusion.

Such an effort is evident in the story of a young man with mental disability who has lived more than half of his twenty-nine years in an institution. Abandoned by his mother and with no family connections, he nevertheless has a personal relationship with God. Although never baptized, he has been active in the facility's Catholic program as both a choir member and sometimes an altar server. Now on the verge of moving out into the community to his own apartment, he has expressed a desire to become a member of the Church. Contact was made with the local parish, and plans are underway to welcome him into a group of catechumens also preparing for the Rite of Christian Initiation for Adults. He may never be able to study the Scriptures or reflect on Papal pronouncements, but his heart will be ready.

" There is a variety of gifts but always the same spirit....; in the one spirit we were all baptized, Jews as well as Greeks, slaves as well as citizens, and one spirit was given to all.... " (*1 Co* 12:4, 14).

Just as that young man will contribute his considerable energy and enthusiasm for the Lord in his new church community, so, too, do all people with disabilities bring gifts to the service of the Lord and his people. I first began to develop an appreciation for what they are able to teach us two decades ago when I became the chapain at a home for disabled children, many of whom had also been abused and abandoned.

Perhaps my favorite of all those with whom I came into contact at Mercy Home for Children in Brooklyn was a young man with mental disability named Frantz. Unimpressed by worldly credentials and unencumbered by material goods, Frantz' goal in life was a simple one: " to be in heaven with Jesus. "

Jean Vanier, founder of the first L'Arche community, notes that it is the ability of persons with mental disability to lead with their heart rather than with their head or their hands that makes them masters in the way of the heart. It is we who are handicapped by our ambitions, our intellect, and our pride from understanding as Saint Exupery's Little Prince put it that " what is essential is invisible to the eye " but detectable by the human heart. In his hunger for love and his willingness to love me for myself and not for what I had or did, Frantz helped me to understand how simple yet profound is the unconditional love of God for each of us. On the occasion of his First Holy Communion, as I was greeting the communicants before the service, Frantz spoke up, " Father Tony, you are bringing Jesus to me today. " " Yes, Frantz, " I replied, " and you are bringing me to Jesus. "

That was a happy day for Frantz, but also one of suffering. I remember watching him turn around a number of times during the liturgy and I knew he was looking for his mother. She did not come. The mystery of suffering is very evident in a young woman with schizophrenia who never knows whether she will recognize herself in the mirror in the morning. For whom sometimes days and months at a time are lost

down the dark hole of her illness. She teaches us that there is no answer to the question of why this is happening to her. We marvel at her faith and her refusal to despair. All we can offer is a response of true compassion—to suffer with her, to be a fellow pilgrim on her journey. Jesus chose to identify with our weakness and our pain, and as the Suffering Servant brought us to new life by his passion and death. So, too, disabled persons for whom physical pain and psychological distress are often constant companions provide us with vivid reminders of how indomitable is the human spirit, carrying their crosses daily with courage, perseverance, and sometimes even joy.

As the blind woman whom I quoted earlier puts it: " God doesn't care if I'm disabled. He still expects me to do my thing. " The disabled members of the Body of Christ challenge us to work out our own salvation, to make use of our own unique gifts and talents because they require no less of themselves. A man who spent more than a decade in a state mental hospital admits that he must " work at being a believer in Christ " but the " joy he experiences from his fellow believers uplifts his spirit and renews his hope. " The mother who lost a beloved son to AIDS now feels called as a person of faith to reach out to others in need of support and reconciliation. The quadriplegic young man who edits a monthly new sletter provides spiritual reading for hundreds of others, many of whom are shut-ins. Unlike the unprofitable servant in Jesus'parable who buried his talent and then made excuses when his master returned, our disabled brothers and sisters make no such excuses for themselves. Can I do less?

Having reflected on our need to be aware of our attitudes toward persons with disabilities, to provide access for them to our buildings and our programs, and to appreciate what their presence teaches us, let me close by recalling the Gospel account of the Risen Lord's appearance to Thomas. Absent on the occasion of Jesus' appearance on the evening of that first Easter Sunday, Thomas remained skeptical of the other disciples' account of having seen the Lord. He demands to see the nailmarks in Jesus' hands and feel the sword's wound in Jesus' side. A week later Jesus returned with Thomas present and the apostle's doubt gave way to a profound profession of faith: " My Lord and my God. " Christ's body still bore the wounds of his passion. Once the marks of his suffering, they now became proof of his transformation into glory. Like Thomas, the world needs proof that the Church is indeed the Body of Christ by the presence of our disabled brothers and sisters among us.

ANTHONY Cardinal BEVILACQUA
Archbishop of Philadelphia

GIULIO ANDREOTTI

Political Commitment and Current Legislation for the Rights of Disabled Persons

It is a very great honor for me to take part in this seventh international conference, which has been promoted by the Pontifical Council for Pastoral Assistance to Health Care Workers and which is dedicated to the presence of handicapped people within society.

The need for the highest international authorities, as well, to be ever more sensitive to this presence is borne out by the recent session of the General Assembly of the United Nations held on the subject of the right of handicapped people to an independent life both within society and within institutions. This session took place within the context of the various assessments underway at the end of the world decade of the handicapped.

My presence here seeks to be a modest testimony to the commitment that those who have received a political mandate must have in relation to the affirmation and promotion of the rights of disabled people.

On the road to this end, which is full of difficulties, a special contribution may be attributed to those many people, political leaders and others, who have given life by Christian inspiration to the principles which are at the basis of the political and legislative action of the Italian state.

This contribution—which is founded upon that Christian anthropology to which this conference also bears witness—has, indeed, determined the fundamental option adopted by the legislature of our country: the guarantee of the rights to equality of handicapped people within a framework of abandonment of a logic of subsidy which too often has not affirmed the equal rights that everybody, including the weakest, have within society.

With this unanimous commitment, there has been a wish to map out a road by which a correct realization of what is upheld in the third article of our Constitution could be achieved. This article may be seen as the rule of solidarity, which is itself a juridical rule and which is the basic reality of life in civil society.

The Constitution, indeed, solemnly proclaimed the inviolable rights of man both as an individual and as regards those social formations where he develops his personality. It affirms the equal dignity and equality of all, without distinction of social or personal status or situation. From an affirmation of this " formal equality " there follow the tasks—indeed, I would say the duties—of a modern democracy: the removal of obstacles of an economic and social character which, because in practice they limit the freedom and the equality of citizens, hinder the full development of the human person and the effective participation of all people in the economic, social, and political life of the country.

From the point of view of these principles I would like to make brief reference to what has been achieved in Italy at both a normative and an operative level as far as regards people with disabilities.

The legislation which has been accumulated both by the state and by the regions covers a vast gamut of needs and rights—from school integration to work integration; from prevention to support (of an economic character as well) of the family and of an individual; from home and hospital health care to fiscal concessions, transport, and the removal of architectural obstacles and impediments; to technical aids, the right to information and communication, and more human forms of scientific research aimed at developing technological and methodological innovations which are effective and efficient, of an acceptable cost, and capable of offering everybody a more fully independent life.

A choice in favor of a systematic legislative instrument of a complex character has emerged as a response to the need to re-direct different fields of action to specific points, to the necessity to obtain a new and " integrated " vision of the

disabled person, and to ideas about a modern social state in Italy. Last February, at the end of the tenth legislature, Parliament approved the " law for the care, social integration, and rights of the handicapped. "

This law reflects the guidelines outlined and suggested by, amongst other bodies, this Pontifical Council and the charitable and welfare works of the Italian Bishops' Conference in their initiatives of February 1991: the overcoming of the tendency to discriminate and marginalize —not to mention the mere giving of relief or subsidies—so as to develop, instead, respect, consideration, interaction, sharing, cooperation, and mutual exchange in places dedicated to education and formation, and in the experience of normal life.

Handicap is considered by this law in its entirety—attention is not only paid to incapacitating pathology but to the whole range of elements of a social, economic and cultural character which act to create a situation of handicap. The achievement of true social integration of the disabled person is an objective aimed at by the institutions in their assessment of the individual's capacities and remaining resources and in their support for the family and associated bodies which work on their behalf.

As is known, culture and politics of a Christian inspiration have always affirmed the centrality of the family in society.

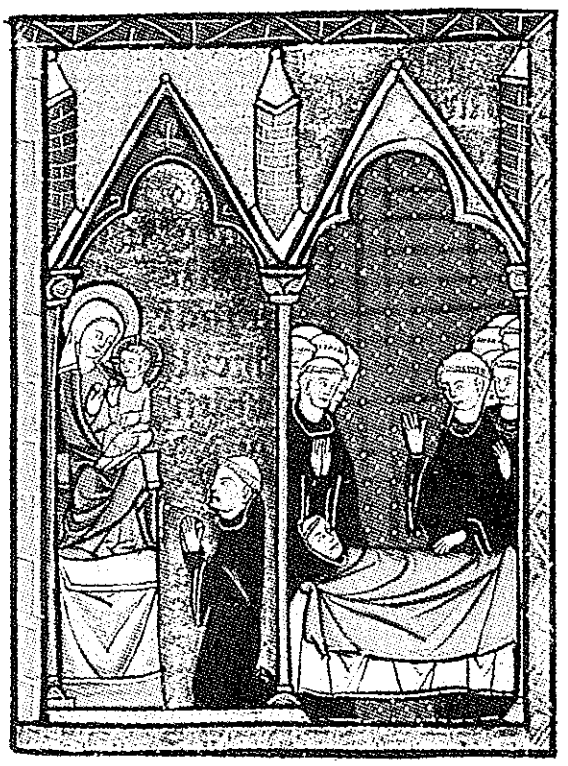
Now, finally, on the part also of secular culture there is a recognition of the irreplaceable role of the family in the achievement of the authentic well-being of the individual. Unfortunately, however, it must be acknowledged that legislation has been late in its provision of support to the family as such.

The same law on disability is oriented towards a recognition of the family's centrality and aims to help it to the greatest extent possible in its choice of keeping within itself and its own immediate environment a relative who is handicapped, and even seriously handicapped, without, however, involving a kind of disclaiming of responsibility on the part of institutions as regards their duty of concrete and practical help.

If therefore, handicap and family—where an actual family is present—make up an inseparable duality which is organized, on the one hand, through an attempt at the personalization of activity designed to help the disabled person and, on the other, through a utilization of all those measures involving family support (home care and assistance of various kinds, benefits for the working members of the family, and so forth), it is also necessary to make a great effort both as regards the cultural approach to the reality of handicap and as concerns the practical provision of services. An integrated coordination of the different institutions at all levels with the social and economic forces is, indeed, clearly necessary.

Today, in Italy, numerous reforms are advocated—electoral reforms, institutional reforms, and party reforms. But there is a further and no less urgent task at hand—the law on the organization of the system of social services.

The economic and financial situation in which our country now finds itself, far from representing a brake on this project, must be seen as an " additional reason " for the implementation of this law. We well know, indeed, that in every



crisis in the end the one who pays the most is the weakest—something which increases the risks of marginalization, poverty, and solitude.

These consequences must be prevented if we do not want to abandon the social state, something that would amount, in fact, to abandoning the basic inspirational source of our Constitution.

Social policy, as is wellknown, is one of the most controversial areas of policy at a European level. During negotiations, Italy contributed through her commitment and her action to the insertion within the treaty of matters which previously had been denied by other nations as being of the Community's purview. Amongst

these, unfortunately, were to be found social questions.

It is to be hoped that all of the countries which signed the treaty and thus overcame their hitherto expressed reservations, will revise their positions and fully recognize that social policy is a matter for common action and that the countries which are candidates for entry—amongst which I am pleased to observe Switzerland—will fully accept this way of looking at things.

This is one of the examples where Italy is placed in the vanguard: her laws contain a high level of guarantee for the rights of the individual and present themselves as yardsticks for projected action to be taken at a Community level.

The law on handicap is one of these laws.

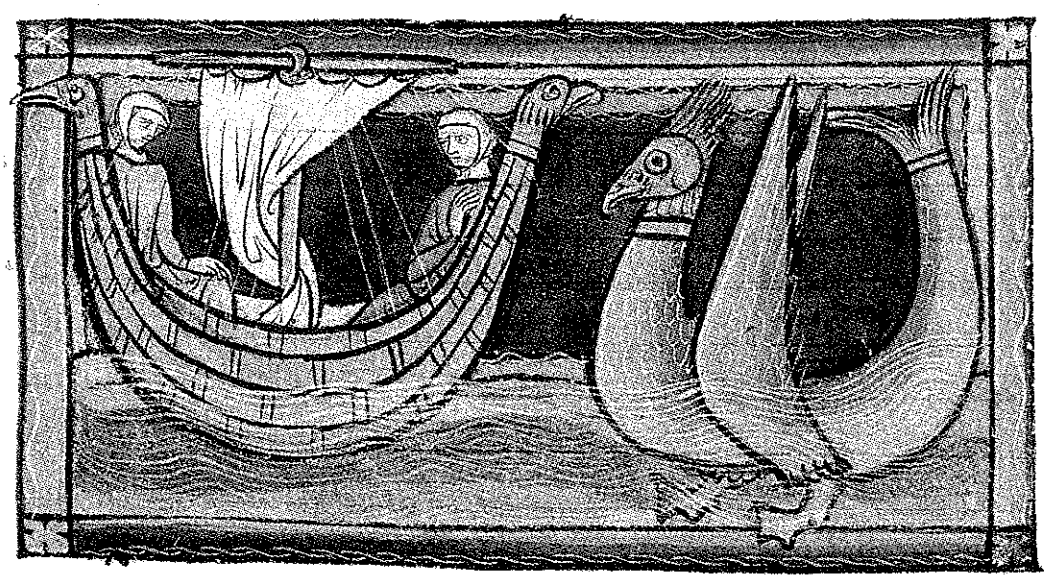
Moreover, if man is the center—both as an individual and in his social dimension—then the handicap problem cannot be approached without reference to this truth. This would lead to sectorial action and not to the full appreciation of the entire social body.

On the contrary, there is a need to perceive that in the construction of a community —whether at a local or international level—one must see those who are weakest (and amongst these the handicapped) not as a limit but as a positive and active force with whom the common society can be built. To be concerned with, and interested in, disabled people really means to refound the whole of society on a human scale.

In our national life a voluntary sector is dedicated to this area. It is composed of religious and nonreligious members, and it must not be reduced by the growing and preponderant action taken by public authorities. Indeed, we must sustain and support certain examples of active solidarity which do honor to the traditions of our country. One need only think of the delicate and meaningful action of long-standing orders dedicated to helping the blind and to the caring help and admirable care furnished in the homes at Cottolengo for those who have been most afflicted by nature.

Let these be the lights which illuminate the paths of future generations! To protect them it seems to me suitable, at a difficult moment of social tension, to invoke that yearning prayer: " Stay with us, Lord, the evening approaches. "

Senator GIULIO ANDREOTTI
Senator for Life
of the Republic of Italy



LOUIS W. SULLIVAN

The Role of Government in the Prevention of Risk Factors

Good afternoon and thank you for that warm welcome.

My role here today is to discuss what I believe governments can do to reduce and even prevent risk factors associated with disabilities.

But I would first like to commend all of you who have gathered here for this historic conference—which not only speaks to the technical aspects of working with people with disabilities, but which also presents an opportunity to examine our values, our hearts, and our spirits as they relate to the vital work that we do on a daily basis.

It is my hope that you leave here refreshed and renewed in your commitment to serve people with disabilities and their families in the best possible manner—using your professional skills to the fullest, but also using your faith as a guide in the days ahead.

As U.S. Secretary of Health and Human Services, I have had the responsibility of managing the world's largest government budget devoted to serving people in need.

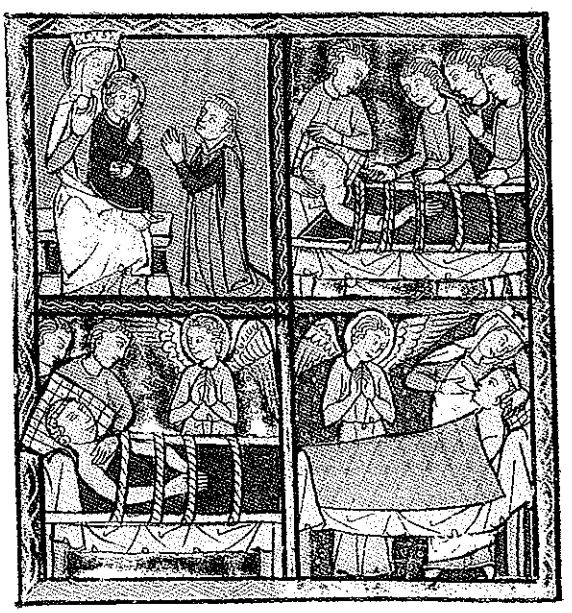
I am proud of the good that our department accomplishes—the pain it alleviates, the opportunities it provides, and the hope it inspires. And yet, so much of what we achieve is in reaction to events or circumstances that could have been avoided with more careful and thoughtful foresight.

This is not to suggest that all negative human experiences are avoidable, or to deny the reality of human suffering. We know that even our best efforts are imperfect in preventing some types of suffering.

Yet, when we look at the circumstances that result in a person or a family coming to seek our help, we often wish that we had met the individual or family earlier—that we could have urged the family to do everything to make sure their child was protected against avoidable disease—that we could have encouraged the teenager to avoid irresponsabile behavior—or that we could have helped the family link up with the resources necessary to support their aging family member at home.

Wishful thinking? I do not think so. For we all have a special role to play in assisting our fellow citizens to become all that they can be. And very often, we can provide this assistance by preventing risk factors associated with human suffering of many kinds.

In the area of disability, we must be clear that what we are not talking about is the elimination of people with disabilities. Regrettably, much of the publicity associated with the prevention of disability focuses far too often on " the horrors " of disability, rather than

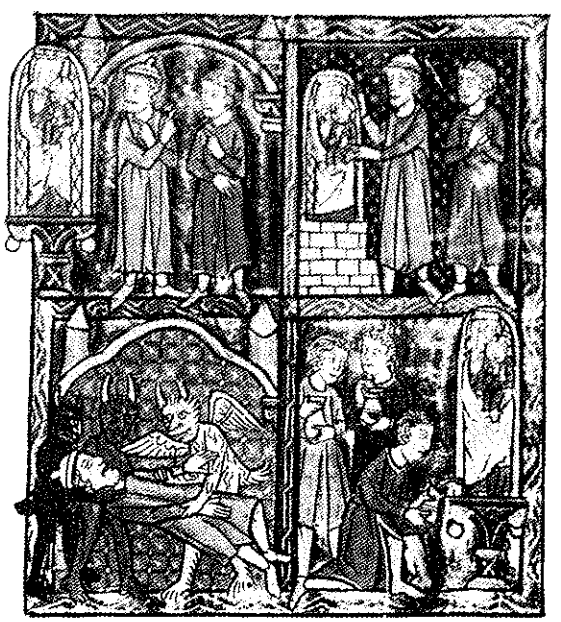


adaptive responses to the needs of human beings.

I prefer to think of prevention efforts in this area as being fueled by a commitment to assisting people in leading the most healthy and satisfying lives possible, avoiding unnecessary pain or inconvenience, and adapting to their limitations in a positive and constructive manner. This, I believe, is the true formula for all of us in leading the best possible lives we can.

What, then, does this imply for governments as they seek to prevent risk factors associated with disability? First, we must renew our commitment to global peace. The world today is far different from the world we lived in four years ago. Still, there are too many places where violence, war, and ethnic hatred create terrible human suffering and leave individuals needlessly impaired for life. So, government leaders of the world must work harder to achieve peace, mutual understanding, and respect. This will help us avoid millions of unnecessary lifelong disabilities.

Secondly, I believe that government leaders of the world need to more completely address environmental concerns. Today, in some parts of the world, children are experiencing lower intellectual functioning simply as a result of the air they breathe. Over one billion people live in highly unsanitary conditions that result in disabling conditions. And millions more do not even have access to clean drinking water.



Third, we must ensure that people have access to the best preventive health care possible. In the United States, we have launched what we call the Healthy People 2000 Program. This program sets specific goals regarding virtually all aspects of preventive health care—from a reduction in infant mortality rate to a substantial increase in immunizations.

One of the cornerstones of the Healthy People 2000 Program is personal responsibility, part of a larger conceptual framework—the development of a culture of character. Simply stated, a culture of character calls upon its members to take personal responsibility for their actions. It asks them to be thoughtful about the impact of their actions on themselves, their families, and other members of society.

Imagine how dramatic the impact on disability would be if people were more thoughtful regarding the potential consequences of their own personal behavior. And, once again, I believe that a culture of character is an achievable human pursuit. In my own country I have seen hardened youth gang members put aside their weapons and re-enter school. I have met with countless individuals who have accepted the call to " just say no " to drugs. And I have seen young mothers leaving behind a life of irresponsible behaviors in favor of ensuring that their babies have the best possible start in life.

Some of this is, of course, financially supported by government programs. Yet, I believe the key to success in this endeavor is found in moral leadership, the ability of government officials to recognize what is right and what is wrong and to have the courage to speak out on these issues. For, while it is often a political risk to speak out, there is great comfort in knowing that, potentially, millions of lives will be better as a result of a single, persuasive act of courage.

Fourth, we must support the families of children and adults with disabilities. In the United States we believe that the family is irreplaceable as the best possible environment for all children, including children with disabilities.

We also know that parenting a child with a disability can be a real challenge. That is why we have moved to provide early help to these families through the provision of respite care, early educational and therapeutic services, and a wide variety of practical family support initiatives. Over 40 of our 50 States now have family support programs and all 50 are participating in the development of educational and therapeutic services that will be available from birth.

In designing these programs we have worked

directly with families and we have sought to ensure that all of them are family-centered.

Provision of practical assistance to help these families will go a long way toward preventing secondary disabilities. This clearly constitutes a wise investment in the future.

Finally, I would like to discuss briefly the role of governments in creating a societal context wherein people with disabilities can be treated with dignity and respect as valued members of their local communities. While some might think that this goes beyond a discussion of " prevention, " I can state unequivocally that development of responsive and inclusionary communities plays a vital role in the prevention of prejudice and negative attitudes—risk factors that in many situations are actually more damaging than a disability itself.

How serious is the impact of prejudice and negative attitudes on the lives of people with disabilities? Sadly, prejudice can literally kill you. Negative attitudes can drive people to utter despair. Forced idleness can lead to further complication of disabilities. The list goes on. We must work together to eliminate prejudice and improve attitudes throughout the world.

The international decade of disabled persons was a significant global effort in this direction. And I am pleased to announce that next year, the National Council on Disability under the leadership of Mrs. Sandra Parrino—herself the parent of a young adult with a disability—will be sponsoring a world-wide conference on this subject at the United Nations in New York.

We must look at the policies and programs in our own countries and determine whether they encourage the presence and participation of people with disabilities in the lives of their local communities, or whether they impede such presence and participation. Where people are excluded, we can infer they are not valued. Where people are included, we can infer that they are seen as valuable.

Many of you are aware of the landmark Americans with Disabilities Act in the United States, the most comprehensive statement of civil rights in the history of disability policy.

As a physician, I see the Americans with Disabilities Act as a strong force against prejudice and against exclusion of those with disabilities. In fact, we in the federal government have already utilized the Americans with Disabilities Act to ensure that there will be no discrimination in access to health care because of disabilities.

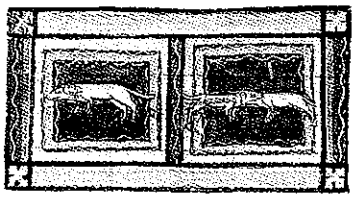
The Americans with Disabilities Act will also alleviate the compounding effects of poverty on disability because it prohibits job discrimination and allows many people with disabilities to enter the job market and escape the cycle of poverty for the first time.

Through application of the standards for physical accessibility to buildings and community resources, people with disabilities will be able to travel through their communities with much greater ease, get to the doctor's office when they need to, and participate in recreation and sports activities in order to improve their physical health and form relationships with others.

Since this will be my last address to a Vatican conference as U.S. Secretary of Health and Human Services, I want to take this opportunity to express my heartfelt appreciation to the Holy Father and to all those responsible for what has proved to be one of the most enlightening and constructive world forums for improving the human condition.

Thank you.

LOUIS W. SULLIVAN, M.D.
U.S. Secretary of Health and Human Services



VALERY BURKOV

Social Policy for Disabled People

First of all, I would like to carry out the important task entrusted to me by the President of the Russian Federation, Boris Yeltsin, and convey, in his name, very warm greetings to those taking part in this Seventh International Conference, on the problems of disabled people; express the wish that all your work will go very well; and communicate that Russia is very ready to help and to cooperate with the organizer of this conference—namely, the Pontifical Council for Pastoral Assistance to Health Care Workers.

The Russian Federation fully agrees with the aims of this conference, which were outlined by Cardinal Angelini in his opening speech. The Federation is fully in favor of bilateral and unilateral cooperation with all those who are concerned with, and interested in, finding solutions to the problems which affect the disabled.

Today, in Russia, notwithstanding all the problems that we have to face which are caused by moving from a totalitarian system to democracy and a market economy, much attention is paid to solving those problems which will be talked about in the course of this conference. The aim of the policy pursued by Russia in this particular area is to ensure the " full participation " and the " equality " of handicapped people in the life of our country.

Today, unfortunately, we have the results of the old policy towards handicapped people, which was virtually limited to the mere payment of pensions or to the construction of special homes. All this led to their social isolation. The recent laws issued by President Yeltsin and the Russian Government attempt to overcome this discrimination. A special role is played by the Coordinating Committee for the Problems of the Disabled of the President of Russia. We should, however, observe that we are only taking the first steps on a road which is by no means easy and which is long.

The Orthodox Church plays an important role in the spiritual rebirth of handicapped people. The Orthodox Church has always sought to help the individual to find work within society which is suited to his abilities. The activities of the Orthodox parish priests are of great relevance here. In order to promote cooperation with public and social bodies, the Synod of the Orthodox Church deliberately created the Office for Charity and Mercy, which does a great deal to help handicapped and disabled people.

Russia attaches great importance to action in conjunction with the UN. The forty-seventh session of the general assembly of the UN, which was held last October, approved a resolution which made December 3 the World Day of the Disabled. We are very pleased that Russia was behind this initiative of the UN. We also think that it would be a good idea to set up a special prize for important achievements in solving the problems of disabled and handicapped people and we would be very grateful if this conference were to support the idea.

In conclusion, I would like to express my sincere conviction that this conference has become an important point of reference on the road to international cooperation in the field of finding solutions to the problems of disabled people. The conference has also shown what a very important role the Church can play in this area.

Russia invites all those present to take part in fruitful cooperation aimed at solving the problems of disabled people and expresses her deeply felt wish to everyone that many successes will be achieved along this road.

I would like to thank you for your kind attention.

Dr VALERY BURKOV
Advisor to the President
of Russia on
Social Policy for Disabled People

HIROSHI NAKAJIMA

The Magnitude of the Problem of Disability in the World

In 1981, the International Year of Disabled Persons marked the beginning of a large-scale campaign to raise public awareness. The United Nations Decade of Disabled Persons has given rise to intensified efforts of information and prevention. It has thus succeeded in reducing the incidence of certain causes of disability. The World Health Organization, which brings together 182 Member States, adopts an attitude of plurality—respect for differences in cultural, social and family backgrounds, systems of values and beliefs, structures of thought, and differences in economic conditions, which determine what is feasible in any form of medical and social activity.

I should like to remind you, in the framework of this conference, that part of the human race is subject to a severe handicap, that is, a structural handicap, relegating it to conditions of marginality that are reflected in the names by which they are described—the Third World and the Fourth World. These are the most vulnerable populations, excluded by a certain model of development and by egotism or thoughtlessness, and they must be brought back to the fold through international cooperation, in a spirit of justice, equity, solidarity, and respect. This is where WHO has its part to play.

While it is true that the magnitude and nature of the problem of disabilities in the world need to be better identified, it is also true that countries need to have a minimum of material resources to cope with them. The dimension of the problem is far from being merely medical. It is also social and economic. It is deeply bound up with the moral imperative of respect for the rights and the dignity of every human being. It is the objective responsibility of each and every one of us and of all societies to comply with this imperative.

The objective of WHO is that people with disabilities should be able to achieve maximum physical and economic autonomy and personal and social development. Any form of exclusion or discrimination must therefore be rejected. It may happen, in some developing countries, that a disability is perceived as a punishment inflicted on the family or the individual for wrongs supposedly committed in an earlier life. The handicapped are then hidden by their families and subjected to measures of segregation.

In cases of this kind, families may react to disabilities in various ways.

— Either they do not understand or do not accept that the disability is permanent. Hoping for a miracle, they go from one center to another, trying all kinds of cures.

— Or they accept the situation passively, remaining ignorant of anything that could be done or improved, with the risk that the disability will get worse and the handicapped person will lose any chance of being integrated into the community.

— The family may also refuse to face the situation and offload the problem through institutionalization. But institutionalization is not always justified and may accentuate feelings of rejection.

In order to reduce the medical problems and the risks of exclusion, WHO advocates what it has termed " community-based rehabilitation. " This is equivalent to primary health care and is organized and provided in and by the community, but oriented in accordance with the needs of the handicapped. This program is receiving very generous support from the Swedish Government.

In these rehabilitation programs, members of the community or community groups work together to provide assistance to people with disabilities and their families. They try to ensure that children attend normal schools, that people

with disabilities receive vocational training, have jobs, and are able to join in the life and activities of the community.

People with disabilities take an active part in the conception, implementation, and evaluation of these programs, either individually or in organized groups. Much of the training needed for the activities of everyday life and social integration can be given by families and communities. But this work must be backed by medical support, with the possibility of referral to specialized services for rehabilitation. These services will give guidance on the nature and graduation of their training, and supply the appropriate equipment and appliances. The objective that countries have set themselves is to have a specialized service in every district hospital.

Finally, as rehabilitation is not confined to medical care alone, it is essential that there should be intersectoral cooperation among the health services, the education and vocational training services, and the social services.

Community-based rehabilitation services have enabled WHO to gather a great deal of useful information. The collection of data in this way gives a better picture of realities and is less aggressive than traditional door-to-door surveys or surveys in schools. Surveys of these types may raise hopes that are then frustrated if nothing is subsequently done for people with disabilities, and have sometimes been used to exclude handicapped children from schools.

In the course of the last two years, the World Health Organization has convened a series of intercountry conferences on rehabilitation in general and on the community-based program in particular, in order to promote cooperation and exchanges. Three workshops have been held in Asia and two in Africa. Half of the countries represented at these consultations have community-based rehabilitation programs and a quarter of the countries have drawn up national programs that are still being tested in a few pilot areas.

At your earlier sessions, you have already discussed the problem of defining disability, covering concepts ranging from infirmity to disablement. You have also been talking statistics. By extrapolation, the number of people with disabilities can be estimated at 500 million, of whom one-third are children and four-fifths live in the developing countries.

We need to be better able to quantify the problem and with it the causes of disability, in order to intervene more effectively in both care and prevention. Malnutrition, congenital or perinatal diseases, communicable and noncommunicable diseases, mental illness, alcohol, and drugs may all give rise to a disability. Disabilities may also be caused by injury, which may in turn be accidental or due to natural or man-made disasters, such as war.

The information gathered in community-based programs shows that a constant proportion of about 1.5% of the overall population appears to be in need of rehabilitation services. But assessments made in urban areas in several developing countries have shown that only 15% of the total number of people with disabilities have access to them. This level drops to 1% in the rural areas. This gives some idea of the magnitude of the problem and the effort required.

Community-based rehabilitation programs bring assistance to 90% of people with disabilities and facilitate their access to referral services. They safeguard the right of children with disabilities to live with their families by making this possible and restoring their mothers' role in their upbringing. Seeing the very encouraging results, many developing countries have expressed their desire to establish or extend programs of this kind.

Since they lack the financial and human resources, however, these countries cannot tackle all their priorities at once. Their specialists or technicians live in the capital and referral services do not cover the whole of the country. A limited number of people are admitted to institutions that are often run by nongovernmental organizations and are not themselves able to provide referral services. It is up to the State to ensure the cohesion of health, social, and educational policies throughout its national territory. Governments and NGOs must ensure that their action is complementary, and the training of local personnel is an essential priority.

There has been greater progress in the prevention of disability in the last decade than in global rehabilitation activities or action to promote equality of opportunity for the handicapped. Disabling diseases could, in practice, be more widely prevented. This is the case for malnutrition, deficiencies in micronutrients, especially iodine and vitamin A, communicable diseases and injuries, which together account for between one-third and one-half of the total cases of infirmity that arise in the developing countries.

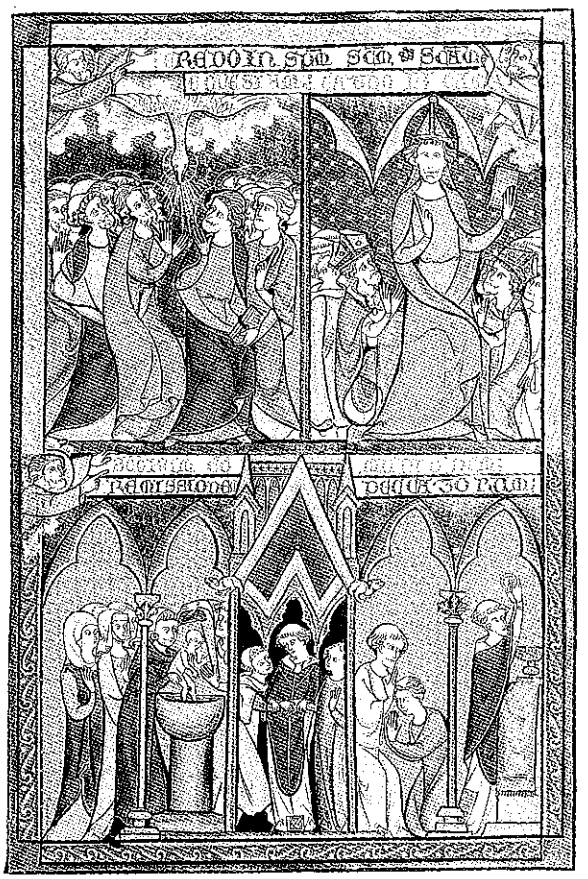
The progress that has been accomplished is essentially the result of systematic campaigns of immunization and the prevention of measles and poliomyelitis. About 445,000 cases of poliomyelitis are prevented every year. The prevention of infectious diseases of the eyes and the WHO Onchocerciasis Control Program have succeeded in reducing the incidence of blindness. The

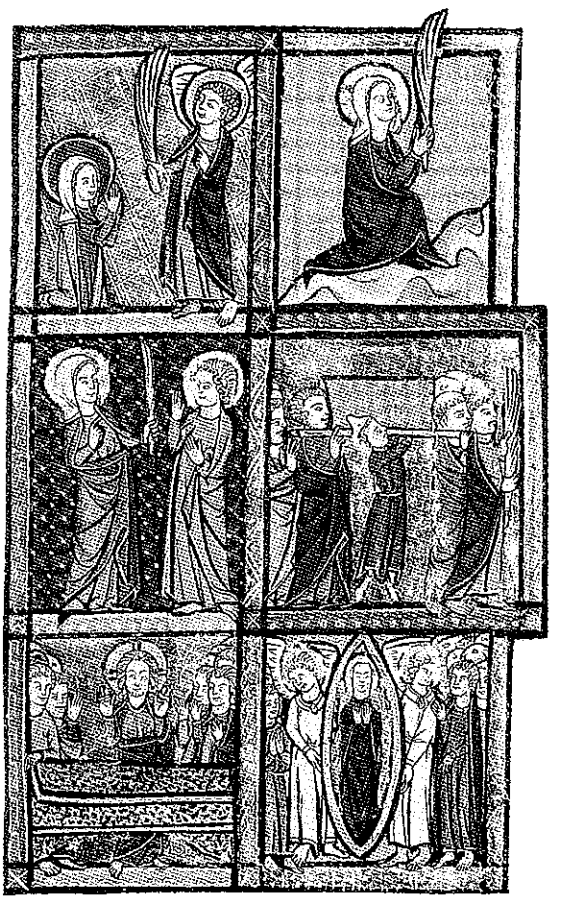
introduction of multidrug therapy has brought down the number of cases of leprosy from 5.4 million in 1985 to 3.1 million in 1992.

In the years to come, however, the number of people with disabilities will increase considerably, especially in the developing countries. In the first place, as a result of two phenomena that are positive: better maternal and child care, resulting in a higher rate of infant survival; and increased life expectancy in the developing countries. There are other contributory factors that are negative but could be addressed by collective efforts at prevention on our part. These are the increasing number of accidents —occupational accidents especially, but also domestic accidents and traffic accidents, and lastly, malnutrition and war.

WHO sees its role in the development of a continuous spectrum of activities, ranging from prevention and prompt diagnosis to prevent the development of secondary disabilities, through to treatment and community-based rehabilitation. It is the aim of WHO to promote the autonomy and welfare of all human beings, and their integration into a human community imbued with solidarity and able at last to live in a world at peace.

Dr. HIROSHI NAKAJIMA
Director-General, World Health Organization





Citation on the Occasion of the Award of the World Health Organization's Health-for-All Gold Medal to His Eminence, Fiorenzo Cardinal Angelini

Few religious leaders in the contemporary world have shown such profound dedication to health and to the health profession as has His Eminence, Fiorenzo Cardinal Angelini. More particularly, Cardinal Angelini has shown by his actions and his writings that he is deeply committed to primary health care and to making it a reality among underserved communities, in Italy and the entire world, especially developing countries. Other areas in which he has shown a special interest include the health of the elderly, the ethical principles of medicine and health care and the protection of the environment.

In 1985, His Holiness Pope John Paul II established the Pontifical Council for Pastoral Assistance to Health Care Workers. His Holiness gave the responsibility of organizing the Council to Cardinal Angelini and appointed him as President, a function he has carried out with great distinction. Under his leadership, the Council has a record of outstanding achievements in the development of preventive and curative measures within the framework of primary health care.

Particularly noteworthy has been the series of international conferences on health issues, including the 1989 conference on AIDS, which Cardinal Angelini organized with dynamism, imagination, and openness. These conferences have brought together Nobel Laureates, health ministers and leading physicians, scientists and humanists, from many different horizons and faiths. The journal that Cardinal Angelini directs, Dolentium Hominum, *published in five languages, has consistently brought a message of hope, compassion, and wisdom to its readers throughout the world.*

The World Health Organization is privileged to present to His Eminence, Fiorenzo Cardinal Angelini, the Health-for-All Gold Medal, in recognition of his outstanding contributions to achievement of the social goal of health for all by the year 2000.

HIROSHI NAKAJIMA, M.D., Ph.D
Director General
World Heath Organization
November 21, 1992

TOMMASO DANIELE

Address by the President of the Italian Union for the Blind

Ladies and Gentlemen,

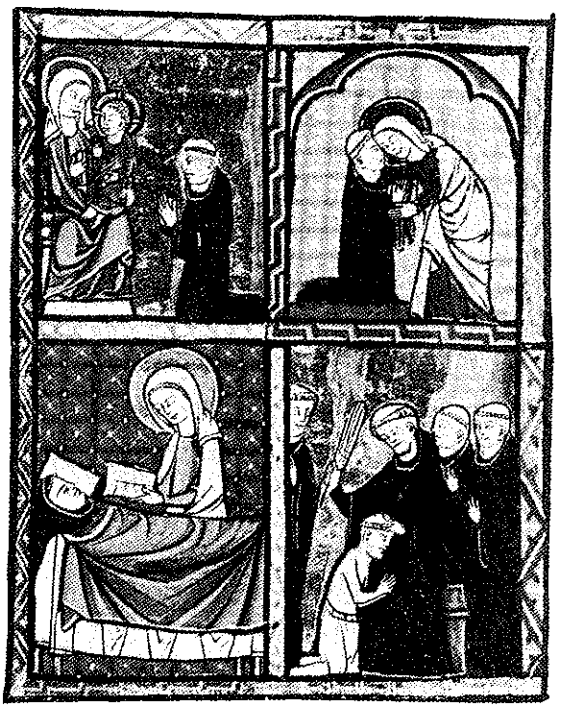
I speak in the name of the Italian blind, whom I have the honor to represent. The time allocated to this contribution of mine is not enough to speak about who we are, our history, about the past, the present, or above all else, the future. I would like you to know only that there are twohundred thousand of us and that, like all blind people the world over, we are engaged in a daily, passionate, and fierce battle for equal opportunity and for equal rights.

This is a dream that we always carry in our hearts, it gives us wings, so to speak, and sometimes allows us to fly. But often, indeed too often, we are overcome by the storms of life and at that moment our dream becomes a nightmare: the fear of being buried alive beneath the weight of various forms of selfishness and indifference grips us and renders the nights we pass a torment.

We live in an age when solidarity finds it difficult to advance amongst the stones and the brushwood which lie along its path. And yet, without solidarity, as John Paul II has written, there is no future, there is no development, and there is no life. This conference represents a unique occasion, a chance which will not come again, to remind man of the true values in life, to sing a hymn to the triumph of the civilization of love. As Tolstoy teaches us, at the heart of man is to be found the beginning and the end of everything—love.

Today we are finally all gathered together —the blind, the deaf, the mute, paraplegics, the mentally afflicted—under the warm and safe wings of the Church. Day after day the Church shows us that this planet, when it comes down to it, is small; that all we need do to embrace each other is to look for each other. The Church also teaches us that it is a thing of beauty to reach out our hands and make gestures of love, of peace, and of justice.

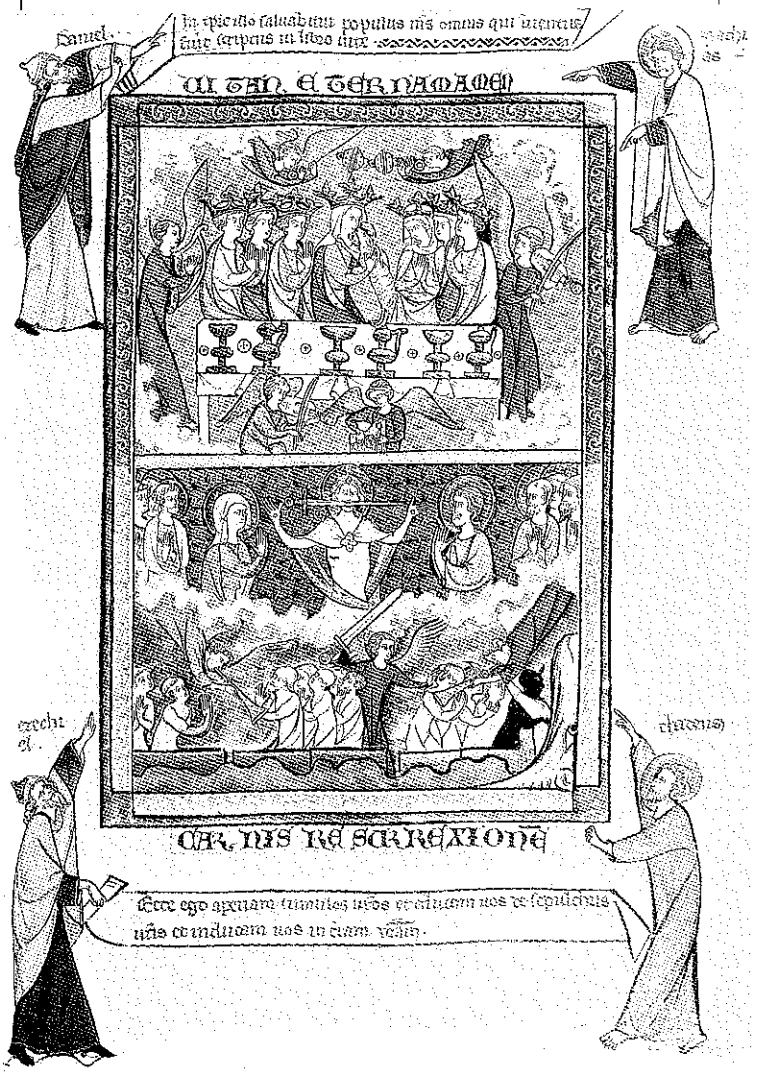
We are here to bear witness to our suffering



and to hold it up as a value, as a source of hope and of life. We are here to affirm our right to exist, to study, to work, and to experience joy. We are here to cry together with one voice to the Secretary General of the United Nations that it is time to pass from awareness to action—as he has made clear in his message—and from words to facts, and to do this in order to guarantee to the five hundred million invalids in the world a life which is worthy of being lived. Our voice does not have the harsh tones of violent protest but the sweet tones of prayer. We want to pray with a clear and strong voice because we are convinced that up above there is someone who loves us.

Professor TOMMASO DANIELE
National President
of the Italian Union
for the Blind

Your Members Are the Body of Christ



Disabled People in Society

ALVIN R. TARLOV

Persons with Disabilities: Definition and Conceptual Framework

My task is to define disability and to advance a common conceptual framework. After defining disability, we will see that disability is not randomly distributed in a population, but preferentially afflicts persons in lower social strata. The disabling process that unfolds in four stages will be described. The social, behavioral, and biological risk factors that are antecedents of disability will be shown to be deeply rooted in the societal structure. The societal structure is a powerful determinant of the unequal distribution of disability throughout a population. The consequences of disability for quality of life and the huge potential of prevention to avoid the waste and suffering of disability will be discussed. First, the definition.

" Disability " is caused by a health condition, and is a restriction of physical or mental functioning in performing socially defined roles and tasks that individuals are expected to do. A health condition can be an inherited abnormality, a congenital anomaly, a developmental problem, abnormalities following injury or chronic disease, or a diminution in capacity that normally accompanies old age. The key phrase in the definition is " socially defined, " meaning that disability is the net interaction between two forces: an individual's physical and mental capacity interacting with the demands and expectations of the surrounding social environment, such as going to school, working, providing for one's family. Diminished capacity per se does not inevitably cause disability. Adjustments in the surrounding social environment can

DISABILITY

Caused by one or more health conditions, disability is a restriction in physical or mental function in performing socially defined roles and tasks that individuals are expected to do.

Table 1

THE DISABLING PROCESS

PATHOLOGY →	IMPAIRMENT →	FUNCTIONAL LIMITATION →	DISABILITY
Cellular and tissue changes caused by infection, injury disease,etc	An organ's loss or diminution of capacity	A person's limited ability to carry out an action	A person's restricted capacity to perform within the social and physical environment
Cells	Organ	The whole person	The whole person interacting within society
Spinal cord severance	Flaccid paralysis of lower limbs	Inability to walk	Restrictions on work, recreation, family life

Table 2

prevent diminished capacity from becoming a disability.

The prevalence of disability is inversely related to income. With lower incomes, there is higher prevalence of disability. It is not just a difference between the poor and the nonpoor. There is a continuous gradient of prevalence across all income categories. If the afflictions that underlie disability occurred randomly throughout a population, these bar graphs would be of equal height. The health gradient shown here is for disability, but similar gradients have been shown for prevalence and death rates for almost all chronic and acute infectious diseases, for death rates overall, and for responsiveness to chemotherapy. The health gradient can be shown for any of the markers of socioeconomic inequality income, as used here, education, housing, neighborhood, minority race status, and so forth. The continuous gradient between health and social inequality has been demonstrated in every nation in which it has been studied. At The Health Institute in Boston, where I work, our research is designed to uncover the root causes of the nonrandom distribution of disease and disability. Some portion of the gradient can be explained by higher rates of tobacco and alcohol use and higher fat diets in the lower income groups. However, the causal explanations go much deeper than that. They are deeply rooted in societal characteristics that foster inequality, such as large gaps in income between high and low income groups; differences in perception of freedom, justice, security, and opportunity; racism; standards of education; neighborhood characteristics, and many others. Improvements in health and disability in any society, developed as well as developing, require interventions at the fundamental structural foundations of society aimed to reduce inequality.

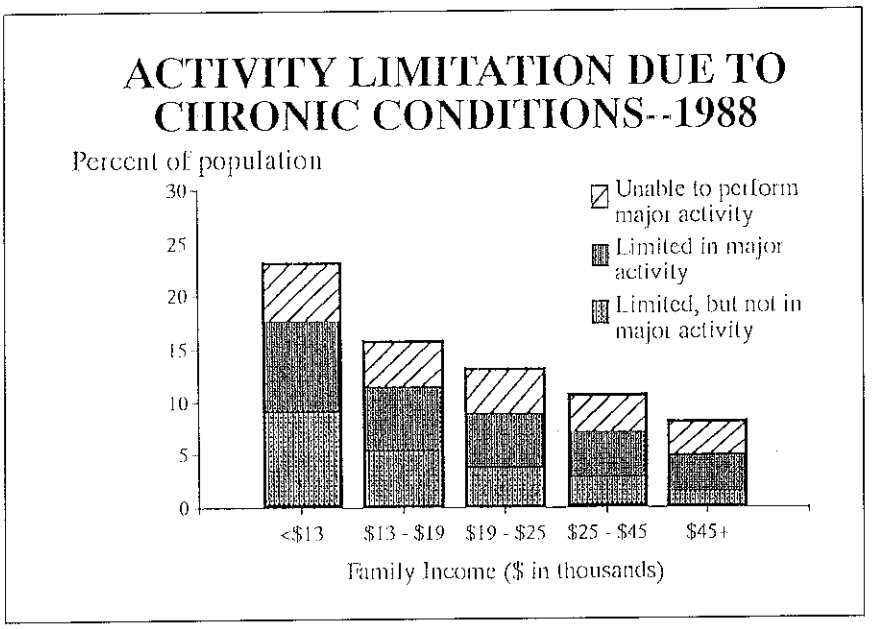


Table 3

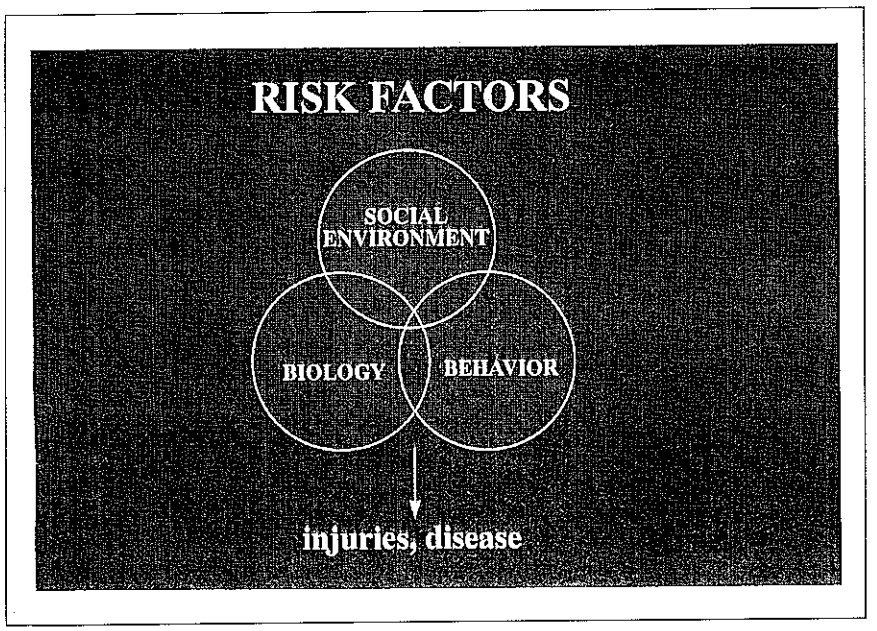


Table 4

The disabling process is outlined in this paper. The framework is modeled after the combined work of Saad Nagi, of Ohio State University, the World Health Organization, and the United States Institute of Medicine Report entitled *Disability in America*. Although this conceptual framework differs in some respects from the International Classification of Impairments, Disabilities, and Handicaps, translation from one model to the other is easily accomplished. We prefer this terminology because it avoids use of the word " handicap " " Handicap " has evolved to imply an absolute limitation independent of the larger context of the social environment in which the person operates. " Handicap " is perceived to be a negative and stigmatizing term in the United States, and, along with the term " cripple, " is approaching obsolescence.

The disability process is comprised of four related but distinct stages: pathology, impairment, functional limitation, and disability. In the course of a chronic disorder one stage can progress to the next. But progressively greater loss of function need not occur, and the progression can be halted or even reversed. Thus, disability prevention can be directed at any of the three stages that precede disability, as well as at the disability stage itself. Efforts can focus on reversal

of disability, restoration of function, primary prevention of the pathology at the root causes, or prevention of complications that can greatly exacerbate existing limitations and lead to new ones.

Pathology refers to cellular changes due to injury, disease, infection, congenital conditions, or other causes. A man is in an automobile crash and sustains fractured lumbar vertebrae and permanent crush injuries to the spinal cord. The pathology is the destroyed cells and tissues of the spinal cord.

Impairment, an inevitable accompaniment of all pathologies, is a diminution or loss of capacity of an organ. The crush injury of the spinal cord leads to a flaccid paralysis of the muscles of the lower limbs, referred to as paraplegia. The impairment is the flaccid paralysis of the muscles.

Functional Limitation defines a limited ability of the person as a whole to perform an action. The functional impairment of a person who has a flaccid paralysis of the lower limbs is an inability to walk. Not all impairments lead to the same degree of functional limitation. Some individuals having flaccid paralysis of the lower limbs can nonetheless train themselves to ambulate by conditioning of accessory muscles, improved cardiovascular fitness, strengthened motivation, and the use of assistive devices such as crutches.

Disability is the expression of a functional limitation in a social context. Disability results when an inability to walk is followed by a diminished capacity to perform socially expected activities and roles within society, such as shopping, attending church, providing for one's family, and helping others. Disability is the gap between a person's functional limitation and the demands of the environment. People with functional limitations are not inherently disabled and incapable of fulfilling personal, family, and social responsibilities. The person who is unable to walk can nonetheless experience complete fulfillment through the use of a wheelchair and elevators on motor vehicles; wheelchair access routes in the home, on the streets, in public buildings and at work; and by modifications in the work space. The interaction of a functional limitation with the social environment determines whether a person has a disability. Disability is not an inevitable consequence of a functional limitation.

Most disability is preventable, either primarily by such actions as avoidance of drinking and driving; or by provision of trauma care to promptly relieve the pressure that a fractured vertebrae exerts on the spinal cord; by improvement of the attitudes, reactions, and motivations of the individual and his family, friends, employers, and organizations that provide services; by rehabilitation; or by environmental modifications that allow people with functional limitations to perform fully.

I have used the example of a spinal cord injury to illustrate the disabling process. The concept is equally applicable to developmental disabilities including hereditary disorders, congenital abnormalities, perinatal conditions, and acquired childhood conditions, as well as to disabling conditions related to mental disease, injuries, chronic disease, and aging. The concept has the distinct advantage of directing us to points where preventive interventions can be effective.

Although understanding the disabling process is valuable, it provides an incomplete model of disability because it does not address the predisposing factors responsible for the unequal distribution throughout society of impairments, limitations, and disability. And it does not incorporate a quality-of-life concept into an understanding of the consequences of disability and the objectives of service. Let's proceed now to complete the conceptual framework.

Risk Factors are predisposing factors that lead to pathology. Risk factors can be biological, such as an inherited propensity to alcohol excess; or behavioral, such as driving an automobile while under the influence of alcohol; or social, such as gross inequality, or societal laxity with respect to the advertising, promotion, sale, distribution, use, and monitoring of alcoholic beverages. Identification of risk factors is the first line of attack in designing interventions to improve health and prevent disability.

This depiction of risk factors as determinants not only of disease but also of the course of the disabling process and the outcomes of health care is intended to convey the interactive dynamics among the three general categories. The detail specification within each sphere can be added by you. Some risk factors, particularly social environmental

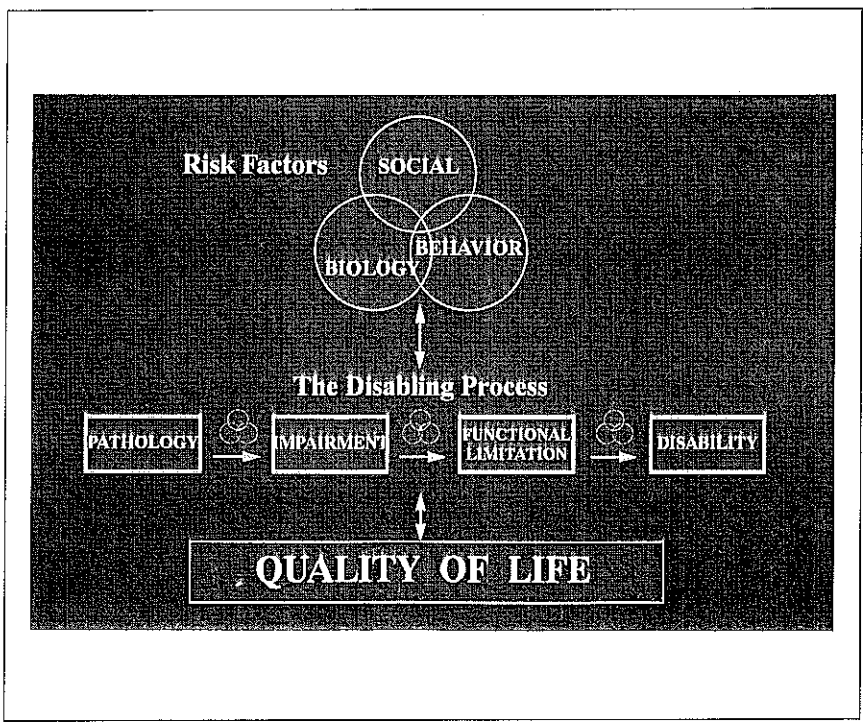


Table 5

ones, confer a general susceptibility and predispose to almost all health adversities. One behavioral risk factor may predispose to multiple diseases, such as tobacco smoking for both heart disease and lung disease. Genetic risk factors ordinarily are specific for one disorder, although combinations of genes may predispose an individual to a chronic disease—heart disease or cancer for example—that doesn't develop unless certain external risk factors are present. Nonetheless, for most health conditions all three categories interacting together are in play. For this conference I have chosen to emphasize the social risk factors as antecedents to disability because they are the least appreciated and the most pervasive.

Quality-of-life. This model of disability shows the interaction of the disabling process with the antecedent risk factors and with the consequential effects on quality-of-life. Quality-of-life is dependent on health as well as on factors outside of health including education, income, housing, transportation, and access to services. Health-related quality-of- life refers to an individual's capacity as affected by health to interact with family, friends, and colleagues in the home, neighborhood, and workplace with a sense of gratification and fulfillment. Given enough time in conversation to express the reasons for wishing to have better health, every person having a disability will use words that relate to quality-of-life.

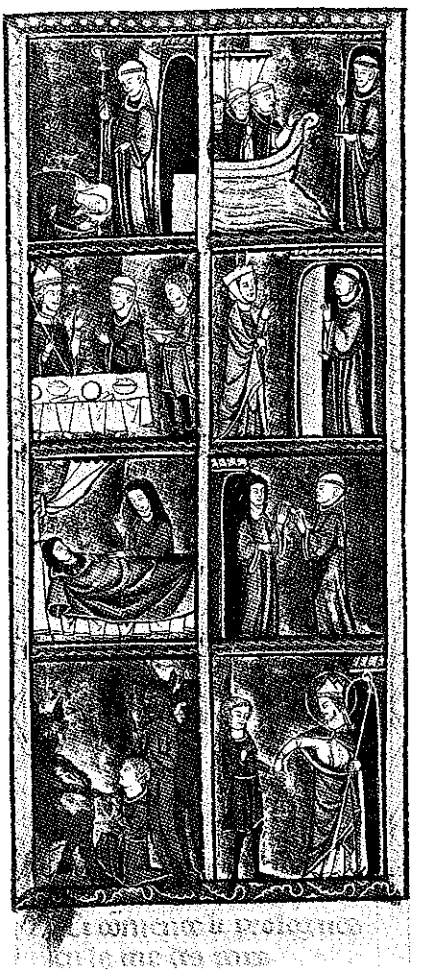
Quality-of-life is mentioned here for three reasons. First, quality-of-life depends on an individual person's assessment of his own status of living. This should be welcomed as a move toward a more humane concern for the whole person from his perspective as an antidote to the highly technical and impersonal directions health care has followed in modern times. Second, quality-of-life measures that have been developed in the past twenty years are simple, inexpensive, precise, and satisfying to patients, and have the potential of establishing new objectives for health services. Third, we should all remember that the purpose of working with persons having a disability is to maintain and improve their quality-of-life.

Bi-directional arrows indicate the potential for reverse causality. For example, functional limitations can predispose an individual to the adoption of behaviors that are negative for health, such as sedentary existence, lack of physical fitness, and obesity, the precursors of heart disease. Or, a person with paraplegia may be vulnerable to the development of bed sores, a nasty secondary condition often leading to sharp compromise in quality-of-life, at least for a few months. And, although the disabling process at each stage causes some compromise of the quality-of-life, the achievement of a more satisfying quality-of-life can substantially help prevent an impairment from becoming a functional limitation, and a functional limitation from becoming a disability.

The depiction conveys that the risk factors can affect the progression at each step from pathology to disability. Most important to the outcomes of the disabling process are the accuracy of the diagnosis, the promptness and quality of treatment and rehabilitation services, financial resources, family and other forms of social and emotional support, and the individual's expectations, morale, and motivation.

From this presentation I hope that you will gain a greater understanding of the antecedents of the disabling process so that greater success can be achieved with prevention. With a greater understanding of the disabling process we will become wiser in our interventions to halt or even to reverse the process. Finally, I hope that all of our good works on behalf of persons with disabilities have as their core objective the maintenance and improvement of their quality of living.

Professor ALVIN R. TARLOV
Harvard School of Public Health and Tufts University School of Medicine Boston, Massachusetts, U S A



ALAN REICH

A Half-Billion People with Disabilities: The World's Agenda

I am deeply honored to be present today. As chairman of the World Committee for the United Nations Decade of Disabled Persons, I want to express our gratitude to Fiorenzo Cardinal Angelini for convening this conference at this historic moment. We are just completing the U.N. Decade of Disabled Persons, and it has been a remarkable ten years. In the strictest sense, we have no miracles to report. The veil of blindness has not yet been lifted, nor has any music breached the wall of deafness. Nor have we thrown away our crutches and wheelchairs, as you can see from those of us gathered here before you.

But in a much larger sense, a kind of miracle is beginning to take shape. It is a transformation of the public spirit. We are seeing people take *their* first steps toward worldwide recognition of our equality, that equality we have always known we had in the sight of God, but are now winning in the eyes of man.

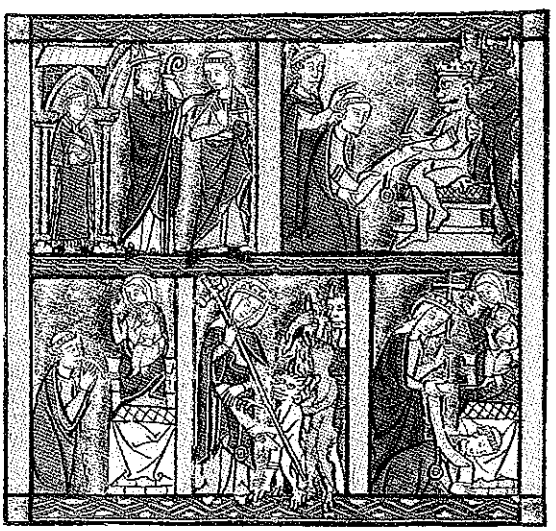
And that you can see too—here today—because so many of us with disabilities are gathered before you.

We come before you—in this same public spirit—to make a great plea. We do so out of many imperatives, including Christian duty. We ask not for your compassion, which we acknowledge and value, but for something even more vital: your advocacy. And we make this plea—those more fortunate among us—on behalf of the entire multitude of people with disabilities—especially those in the developing world who do not share our good fortune.

When I speak of " our good fortune, " I offer such words without stint or irony. During this Decade of Disabled Persons, for example, we have achieved a new legal status in my own country. Two years ago, the United States Congress—acting on the will of the people—passed a bill of rights for people with disabilities. Some 43 million of us now enjoy the protection of the law. The Americans with Disabilities Act mandates public access and equal treatment throughout our society.

But as praiseworthy as such social actions are, they do not reach—and cannot reach—the vast numbers of those less fortunate who have disabilities. Too many of us around the world, by far the greater multitude, are considered what Egypt's President Nasser once called " the human dust. " Struggling up from the dust, they bear a double burden—their disabilities plus the terrible weight that always falls too heavily upon the poor on this earth. They cannot be here today, so it is up to us to make their presence known.

There are some 500 million men, women, and children with physical or mental disabilities, and 85 of them live at life's perilous edge in the developing world. If present trends continue, in another twenty-five years humankind will include 200 million more people with disabilities. When we consider their families, we can fairly say that over



a billion human souls are directly affected now. The Church's great teaching is that we are all equal in the sight of God—even those who may be without sight. But how do those among us who are struggling daily to rise from this " human dust "—some half-billion people with disabilities—how do these enter not only into the house of God, but into the hearts of others?

For their sake, we recognize that there continues to be a great need for worldwide charity. The Church speaks of persons with disabilities as being the same in body as the wounded and suffering Christ. Many of us still must be helped to a better life through God's grace and mankind's generosity. But however broken we are in body, in the eyes of God we are not one whit less than any other living soul. There is, in truth, another Christian view of ourselves. And it is that by our own actions, we can become one with the resurrected Christ. Every rehabilitation, every triumph over physical or mental limitation is a resurrection. We can then share in the communal life of mankind, take up our part in God's mission within His house. That, finally, must be our wholeness.

But this journey to wholeness is not yet open to all of us. For all to arrive there, we must still work to alleviate the harsh conditions for too many people with disabilities. As I have said, many in the developing world are doubly disadvantaged—by malnutrition, disease, lack of shelter, environmental damage, intolerance, and even war. Lately we see a growing and desperate violence. People who are already hobbled are further maimed by inhuman brutality.

A young Liberian organizes a support group for those with disabilities in the city of Monrovia. He can only " crawl " from place to place himself, but he still gathers a thousand people together as the " Liberia Handicap Organization. " Then civil war comes. 280 die of starvation, another 80 are killed in the crossfire while out searching for food, and 230 are killed when his center is bombarded. He himself is intimidated, shot in the arm, because his tormenters believe his tiny organization must be hiding money. But he keeps going, at a crawl, to help 1200 more people with disabilities confront their fate in that hostile city.

That is the kind of courage we find among those with disabilities, in small, brave movements all around the globe. And there are " little miracles " occurring. In Costa Rica, volunteer doctors have conducted 232 operations to restore hearing to children. In the words of that country's First Lady, who sponsors these doctors, the children " can now hear music, the song of a little bird, the sound of rain, or simply the voice of their parents, who call them by their name. "

Thus do we pursue social action, courageous initiatives, and, yes, even miracles. Such is the hope we place in the future, despite so many present horrors. A fifth of the world's population can yet be helped to a fuller, better life if we will only, as United Nations Secretary General Boutros-Ghali has said, " turn awareness into action. " The U.N. Decade of Disabled Persons has brought awareness, but it has also left a legacy that must be taken up and fulfilled through worldwide action. I see a world agenda, having five goals:

Our Lord's great mission here on earth was one of healing. Therefore, *Goal One*: Conquer disabling conditions, scientifically and medically, so that people may be healed. I envision a worldwide effort to restore sight, hearing, movement, and communication. It must include attacking disabling diseases like leprosy, river blindness, polio, and such ravages of childhood as diphtheria and measles—all of which can be prevented.

" In my house, " said Our Lord, " are many mansions. " To enter those mansions, *Goal Two*: Provide worldwide access for people with disabilities across all barriers. Even up to the heavens, there should be, for some, a ramp. But until that Judgment Day, I envision the removal of all barriers to allow worldwide participation of people with disabilities in everyday life —communal and, spiritual—here on earth.

" No man is an island. Every man is a piece of the continent, " preached John Donne. *Goal Three*: Involve everyone in a worldwide effort to expand the participation of people with disabilities in the life of their communities. We know we are all a piece of Africa, South America, the Indian subcontinent, the South of our planet. And I envision a worldwide call to conscience for greater acceptance of

people with disabilities into the family of man.

" The last, " Our Lord also said, shall be first. But for that to happen, *Goal Four*: Undertake the worldwide expansion of education and training for people with disabilities. I foresee a day, however distant, when the skills of people with disabilities can at last be brought to bear upon worldwide solutions to prevailing distress.

Finally, there is the understanding of man offered by Our Lord, in the gospel according to St. Mark:

Neither do men light a candle, and put it under a bushel; but on a candlestick; and it giveth light unto all that are within the house.

Perhaps those of us with disabilities understand better than others about that bushel, which, of course, means a basket. We know what it is like, when it cannot be helped, to have our light suddenly thrust under a bushel. All of us have known, like the poet John Milton, what it is to lose some talent that it is death to hide. To have such talent:

Lodged with me useless, though my soul more bent to serve therewith my Maker, and present My true account.

We all wish to present our true account, and therefore, *Goal Five*: Expand opportunities for work, thus releasing great untapped human potential among people with disabilities, for the benefit of all mankind. This is a very modern, but timelessly moral imperative. And it speaks to the teaching of *Centesimus Annus*, the Encyclical on the 100th Anniversary of *Rerum Novarum*.

Your Holiness writes that human work—which those with disabilities must somehow find across this earth—" is becoming increasingly important as the productive factor both of nonmaterial and material wealth. " Yet the poor, Your Holiness further writes, now lack " knowledge and training, which prevent them from escaping their state of humiliating subjection. " So it will continue to be until the worth of every human being, including those with disabilities, stands revealed through the dignity of work—until every man's and every woman's potential is realized in this too implacable world.

Against whatever hindrance, all of us around the world long to put forth our talents. That is the passion that must move all of us to act. We must never yield to that greatest of all disabilities, under which St. Thomas so long labored—*doubt*.

We must reach to put our light on a candlestick—however high we must stretch, out of whatever darkness. It is the only way that those half-billion of us with disabilities can come forth into God's promise of life.

So we ask for your prayers for our well-being—and for our strength and fortitude. But, with new hope at the conclusion of the United Nations Decade of Disabled Persons, we also make bold to ask that you speak, through an Encyclical on Humankind and Disability, to the moral imperative that demands the half-billion disabled be brought forth into the shared life of this world. We ask that, through such a document—and all your teachings—you assert your moral authority on behalf of those of us with disabilities, so that together all humankind can pursue these five goals as a bimillennial mission. We ask you to help us toll these five goals forth to all Christendom and beyond to world opinion. And we entreat you to help us implement them—not only through God's compassion, but through the advocacy, and religious practices, of His Church.

What more appropriate mission, on the verge of the third millennium of Our Lord, who so often asked that those sore in body and spirit—all ye who labor and are heavy laden—come unto Him, who taught that we must never hide our candle, but set it on high for everyone to see? It will be a long, hard reach for many of us, but it is the only way to give light unto all who live, and work, and love each other within God's house.

Professor ALAN REICH
Chairman of the World Commission for the Decade of Disabled Persons, USA

WOLDEMICHAEL NEGUSSIE

Rehabilitation Services for the Disabled in Ethiopia

Introduction

In Ethiopia in the period when people earned their living exclusively by farming and lived in small villages, disabled persons did not move far from their villages, but remained within the community. Some were occupied and made themselves useful as best as their disability could permit. Some were helped or supported by the extended family or the community. Others went out, beginning from village to village or around Churches, Monasteries, or Mosques. Only a few who lacked the ability to move around or the mentally deranged were a real burden to the family.

With the advent of urbanization, modernization and the rapid increase of the population there has been massive migration of population from the rural to the urban areas. Many disabled people also flocked to the cities and started earning their living as beggars and swelled the number of the dwellers of the city slums

The introduction of modern methods of rehabilitation in Ethiopia

The first institution for the care of people suffering from leprosy was established in Bissidimo around Harar, 500 kms. east of Addis Ababa, by Catholic missionaries in 1900, that is, 92 years ago (1). In 1917 the first blind school was opened in Dembidollo, 650 kms. west of Addis Ababa, by foreign missionaries (2). Later on, in 1934 a second leprosarium was opened on the outskirts of Addis Ababa (3).

The Ethiopian National Association of the Blind and the Ethiopian National Association of the Deaf were established in 1960 and 1971 respectively. The objective of these two associations was and is advocacy for the well-being of the persons with sight and hearing impairments and their rehabilitation so as to make them self sufficient as much as possible (1,4).

The Cheshire Home for Physically Handicapped Children started its activity in 1964 and is now situated 27 kms west of Addis Ababa. It deals mainly with children suffering from postpolio paralysis, and is sponsored by voluntary organizations and individual donors and administered by a board (5).

The Rehabilitation Agency for the Disabled, which later on assumed the name simply, of Rehabilitation Agency, is a specialized governmental organization under the Ministry of Labor and Social Affairs. It was established by proclamation in 1971. It initiates projects and runs various receiving, training, and placement centers for those suffering from various kinds of disability, as well as production centers which employ disabled persons. It coordinates the services of nongovernmental organizations which give services to the disabled (1).

At present there are about 80 centers for the rehabilitation of the disabled in Ethiopia (1).

The magnitude of the problem of the disabled in Ethiopia

It has been estimated " that the disabled comprise about 10% of the world population " (6). In Ethiopia, with an estimated population of 50 million (in 1990), the number of the disabled would amount to 5 million, and 50% of these would be children below the age of 15 or 16 years

According to the 1984 Population and Housing Census of Ethiopia, in which disabled persons were also counted, the total number of disabled people was found to be 3.6% of the population (7).

In a more recent community-based study of Neurological Disorders in Central Ethiopia, in which nonneurological disorders were also involved, the number of the disabled was found to be 2.2 million, or 4.4% of the population (table 1) (8).

Causes of disability

In developing countries malnutrition, infectious diseases, poor perinatal care, and accidents are responsible for about 70% of cases of disability (6). Hospital based studies lend support that this fact is true for Ethiopia, where malnutrition, neonatal disorders, infectious diseases, and accidents are the leading causes of morbidity and mortality in infancy and childhood (9,10).

Four major types or categories of impairment or disability are usually recognized.

1. Visual impairment or blindness

2. Hearing and speech impairments or deafness and deafmutism.

3. Motor or locomotor impairment.

4. Mental impairment

To these (during childhood) one could add epilepsy, an impairment which can result in disability and handicap. It is the most common neurological disorder in children in Ethiopia (8)

Rehabilitation services in Ethiopia today

1. *Rehabilitation services for the blind*

The number of persons with visual implaiment has been estimated to be over 700,000, of whom 75% suffer from total blindness (8).

Excluding trachoma, which affects from 30 to 100% of the total population (11), inflammatory diseases of the eyes ranked 11th among the top 20 diagnoses of all new outpatients in Ethiopia in 1989, and the fifth most common cause of morbidity in infants below the age of one year (12)

In Ethiopia there are now ten centers for the rehabilitation of the blind. Their activities range from purely academic or vocational to socioeconomic rehabilitation. Three such centers are situated in or around Addis Ababa; seven are situated in towns throughout the country (table 2) (13).

Sebbeta School for the Blind. This is one of the oldest blind schools. It is situated 30 kms. west of Addis Ababa. It gives academic education to 209 grade 1 to 6, and to 119 junior and senior secondary school students. It is administered by the Ministry of Education.

Shashemene School for the Blind. It is situated 250 kms. south of Addis Ababa. It gives academic education from grade 1 to 6 to 130 blind students who also get food and shelter. Besides, it gives vocational and agricultural training. Every year there are more than 100 applicants who seek admission, but only 15 to 20 can be accommodated. The school is sponsored by the Ethiopian Catholic Church.

There are several production centers in Addis Ababa and in other towns administered by the Ethiopian Association of the Blind and the Christoffel Blinden Mission,

Table 1 - Disorders causing disability in Ethiopia *

Diagnosis	Prevalence per 100,000	Total no ** in the country
BLINDNESS		
both eyes	1072	536,000
one eye	368	184,000
optic atrophy	16	8,000
DEAFNESS & DEAF-MUTISM		
total deafness	421	210,000
partial deafness	72	36,000
MOTOR DISABILITY		
polio	242	121,000
leprosy	103	51,500
miscellaneous	1282	641,000
MENTAL RETARDATION	169	84,500
EPILEPSY	520	260,000
OTHERS UNSPECIFIED	131	65,500
Total		2,198,000

* Adapted from: Tekle Haimanot R *et al.* Community-Based Study on Neurological Disorders in Rural Central Ethiopia *Neuroepidemiology* 1990: 9: 263-277

** The total number was calculated from estimated population of 50 million

Table 2 - Centers for the rehabilitation of the blind

1. Sebbeta School for the Blind	Shoa (30 Kms west of A. A.); Ministry of Education; Academic education
2. Abraha Batha School for the Blind:	Asmara (Eritrea); Ministry of Education; Academic education up to grade 6
3. Shashemene School for the Blind:	Shashemane (Shoa); Ethiopian cathol Church; Pre-school program/Academic education up to grade 6 vocational training/agriculture
4. Gimbi School for the Blind:	Ghimbi (Wollega); Ethiopian evangelical Church, Mekane Yesus; Academic education up to grade 6
5. Wolaita Sodo Education and Production Center:	Wolaita Sodo (Shoa); Eht. national ass. of the blind (ENAB) and Christoffe Blinden Mission (CBM); Academic education up to grade 6 production/agriculture
6. Bako Vocational School and Production Center:	Bako (Shoa); ENAB and CBM; Academic education up to grade 6 and vocational training
7. Dire Dawa Production and Training Center:	Dire Dawa; ENAB and CBM; vocational training and production
8. Adis Abeba Production Center n. 1:	Addis Abeba; ENAB and CBM; production
9. Addis Abeba Production Center n. 2:	Addis Abeba; ENAB and CBM; production
10. Gimbi Production Center:	Ghimbi (Wollega); self supporting; production

which employ more than 300 blind adults. Three blind schools outside of Addis Ababa (in Welayta Sodo, Bako, and Dire Dawa) are also sponsored and administered jointly by the Ethiopian Association of the Blind and Christoffel Blinden Mission.

The Cimbi School for the Blind is sponsored by the Ethiopian Evangelical Church, Mekane Yesus, and has 78 students. The Gimbi Production Center is self-supporting.

Altogether, there are 519 blind students in special schools for the blind and 230 students in the normal junior and senior high schools. There are also blind students enrolled at Teachers Training Colleges and at the Addis Ababa University.

2. *Rehabilitation services for the deaf (and deaf and dumb)*

The number of people with hearing and hearing and speech impairment in Ethiopia is estimated to be 250,000, of whom 80% suffer from total deafness (affecting both ears). In 60% of the cases the cause is of infectious origin (8).

Altogether, there are 12 schools for the deaf with a total of 752 students in 10 schools. Six schools are situated in and around Addis Ababa and six in towns throughout the country. Five are administered by the Ministry of Education, and four of these are housed in separate units in normal school compounds. Seven are sponsored by nongovernmental organizations and all are situated outside of Addis Ababa, except one. Special education for the deaf includes sign language, which is the medium of instruction. Academic education is given up to grades 4 to 8. Those who succeed in the lower grades may join the junior and senior secondary schools, or go into a vocational training program.

One official of the Ethiopian Association of the Deaf, who is deaf himself, complained that the services given to deaf students are far from being adequate for the following reasons: (4)

a) Lack of understanding of normally hearing people that spoken language is foreign to the deaf.

b) Lack of teaching materials and books suitable for teaching the deaf.

c) Lack of specialized and qualified teachers in deaf schools.

d) The carelessness of integrating deaf students into regular classes with normally hearing students without support services making the education of grade, 9 to 12 deaf students painful and fruitless

e) Absence of vocational training institutions for the " deaf, thus contributing to the lack of job opportunities and hindering the deaf from becoming economically self sufficient..., etc.

3. *Rehabilitation services for motor or locomotor disability*

Prevalence and causes of motor disabilities are listed in Table 1. To these one may add neurolathyrism and ergotism, which appear in epidemics in areas hit by drought and famine (14,15). In Ethiopia there are several governmental and nongovernmental agencies participating in the rehabilitation of leprosy patients, as well as those with motor disability from other causes. With the introduction of multi-drug therapy, leprosy is now believed to be a curable disease. In fact, the number of leprosy patients registered for treatment fell from 82,000 in 1982 to 16,000 in 1991 (1).

The following are some of the agencies and centers working for the rehabilitation of persons with motor disability

The rehabilitation agency: it administers seven receiving and training centers for a total of 3000 disabled persons of all categories. It also administers four sheltered workshops employing 700 disabled men and women, and two Prosthetics and Orthotics workshops.

The United Ability Company. This center manufactures umbrellas and employs 500 disabled persons of all categories; it is sponsored by the Ministry of Industry.

The Hero Center, catering to disabled war veterans (45,000), is situated 50 kms. from Addis Ababa. It is the largest and best equipped center in Ethiopia It provides the most comprehensive rehabilitation services and has a fully equipped Prosthetics Orthotics workshop and produces a variety of artificial appliances.

The Cheshire Home for Physically Handicapped Children gives temporary shelter, and food, as well as physical rehabilitation services, to children suffering from post-polio paralysis. It can accommodate 60-70 children and it also gives services in different localities outside of the center in Addis Ababa and outside of the city through its mobile team In about 14 years it has registered 6,000 children with residual poliomyelitis.

The Home for the Physically Handicapped at Jigessa 250 kms. south of Addis Ababa; gives rehabilitation services to children suffering from post-polio paralysis, as well as children with congenital and acquired malformations of the musculo-skeletal system It can accommodate 45-50 children and is sponsored by The Ethiopian Catholic Church. In the last 5 years 950 children have been physically rehabilitated in this center

4. *Rehabilitation services for the mentally retarded*

Centers for the care of the mentally retarded started to appear only recently. At present there are eight centers; six are situated in Addis Ababa and two in other towns. Three are administered by the Ministry of Education and are day-care centers. The remaining five are sponsored by religious organizations. Services range from provision of shelter, food, and health care to day-care centers in which the children are taught self-help skills and sometimes vocational training, when feasible.

5. *Services for epileptic children*

Prevalence of epilepsy is estimated to be 5-8 per thousand in Ethiopia. It has long been pointed out that it is a chronic disabling and crippling disease if not managed properly and in time (16).

Most people in Ethiopia believe that epilepsy is due to possession by evil spirits or demons. Those suffering from epilepsy or parents of epileptic children do not seek medical advice. They first try the traditional mode of therapy from the local healer or faith-therapy based on holy-water bathing in different churches or holy-places entailing extensive traveling and financial burdens.

Two or three years later, when every traditional mode of therapy fails, the patient is brought to the hospital or clinic. Here doctors or other health workers may not be familiar with the disease or the health institution may lack the necessary antiepileptic drugs. The patient is then referred to a central referral hospital with much discomfort, financial burden, and consequent disenchantment with modern medical institutions. It is not surprising, therefore, to see poor compliance, frequent interruptions of drug therapy, and consequent severe life-threatening attacks of seizure in many epileptics.

Future trends in rehabilitation services

It has long been clear to those engaged in rehabilitation services that there is a big gap between what is being accomplished to help the disabled and what needs to be accomplished Some of the reasons given for this discrepancy are the following (1):

a) That the institutionalized approach of providing services is very expensive.

b) It caters to a limited number of persons.

c) Facilities and services are located in few city centers and are out of reach for most rural communities, where 90% of the population lives

For the above reasons the Rehabilitation Agency, in collaboration with international organizations such as ILO, UNICEF, UNDP, and others, began developing an alternative approach, namely, the Community-Based Approach. It relies on the utilization of as many community and governmental resources as possible in order to provide services to disabled persons in as many parts of the country as possible (17).

This approach is at its initial stage and is being undertaken on a pilot-project basis.

Constraints in the provision of rehabilitation services in Ethiopia (1)

The following are some of the constraints:

1. Shortage of funds

2. Shortage of qualified manpower.

3. Lack of data for planning.

4. Prevalence of negative attitudes among the public and among the disabled themselves.

5. Problem of placement opportunities for disabled persons.

6. Problem of marketing of products.

7 Shortage of supply of artificial appliances, aids, and devices.

Conclusion

Ethiopia is just emerging from a 30-year period of civil war and two decades of devastating drought and famine. During this period hundreds of thousands lost their lives and tens of thousands became disabled. There is now peace in the country. The old, centralized administration is being replaced by a

decentralized one, in which local authorities at the periphery will have greater executive powers.

It is hoped that a more favorable atmosphere will be created in the country for improved preventive, formative, curative, and rehabilitative services at the national as well as the community level.

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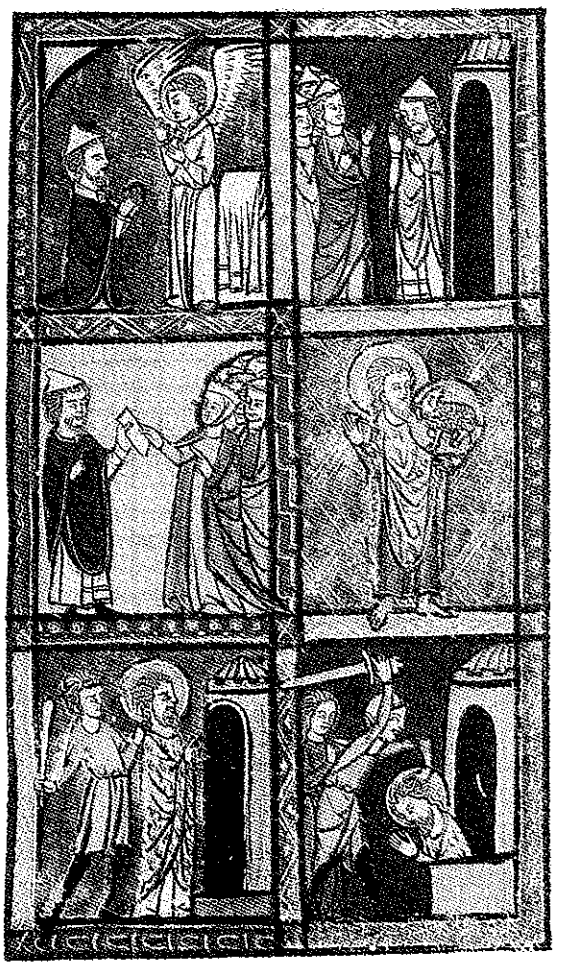


SABINE BERGMANN - POHL

The Handicapped in Our Society

The aim of the social integration of the handicapped is now regarded by the western industrial societies as a question of facing up objectively to our responsibilities.

In Eastern Europe, on the other hand, this burdensome process is only beginning. Even though in many other countries the attempts of the handicapped to carve out a position for themselves in normal society continue to encounter many difficulties.

Possibilities and risks arising from genetic technology

Humanitarian assistance and integration: these are the subjects which always take priority when we discuss " the handicapped in our society, " and they are undoubtedly important, and we are right to discuss them, but there are also other aspects to take into consideration.

We therefore believe that this conference has taken a wise decision in its aim to dedicate considerable space to the themes of scientific research and technical progress in the field of medicine.

It is in this latter sector that we find ourselves at the beginnings of a phase of development which offers significant possibilities, but also risks for the handicapped, and a perfect example of this is the progress made in genetic technology.

We can, in fact, affirm that no other discipline will have as great an influence on human medicine and, consequently, society as a whole as genetic technology.

Only a few years ago the progress made by scientific research on human idioplasm, in the field of genome analysis, for example, would have been absolutely inconceivable.

Genome analysis

The medium objective of the " human genome project " is the mapping of the human genome, which will enable us to directly localize the newly identified genes or genetic fragments on the genome, that is, on the 23 2x chromosomes. The smallest chromosome has already been completely mapped, and we believe that an approximate map of the human genome will be traceable by the end of next year.

The long-term objective of this project is the decoding of all the genes, that is, the sequential order of the codifying genes, followed by the entire sequence of the human genome.

This will lead to a significant increase in the possibilities of base medical research, diagnosis, and the treatment of the various pathologies. Perhaps with the aid of the new genetic methodologies we will even be able to develop therapeutic treatments which up to now have been considered impossible, for example, against tumors and cardiac and circulation diseases.

Genome analysis can already be successfully applied to obtain general information on individual genetic situations for preconception and prenatal consultancy, the screening of the newly-born, pre-transplant diagnosis, and in the context of genetic therapy.

The diagnositc possibilities of human genetics have also grown considerably. We need only mention chromosome analysis, which enables us, among other factors, to identify such serious prenatal patologies as Down's syndrome (trisomy 21)

By means of processes involving genetic technology, we are now able to forecast the presence of Huntington's chorea with an almost 100% probability.

This offers great potential for the safeguarding of life and health, as the more rapidly we are able to diagnose a particular illness, the sooner we will be able to combat it by means of suitable therapeutic instruments.

The growth of our responsibility

However, as the development of genetic technology advances, our responsibilities increase at the same rhythm. We must constantly ask ourselves if it really is correct to do what we are able to do.

If we take, for example, the discussion on so-called " therapy of the germinal pathway, " we can see that there are many of us who look upon genetic therapy with great hope and great fear at the same time.

The Federal Republic of Germany has taken its decision: *there will be no* " therapy of the germinal pathway. " Our precise desire is to exclude any kind of modification of man's genetic heritage that may be transmitted to the generation that follows

Genetic therapy " at a somatic level "

" Genetic therapy at a somatic level, " on the other hand, offers significant possibilities. This is a method of treatment that enables us to correct the diseased cells of the organism by means of genetic surgery, but without passing on the information transferred to the future offspring of the patient.

In the last few years, the first genetic therapies at somatic level have already been applied with success in the USA, for example, in the treatment of congenital immunodeficiency conditions.

First successes in congenital deficiency of the immune system

You will all have seen that terrible photograph of children who are destined to spend their whole lives under a plastic curtain because of this congenital deficiency in their organisms. They will never be able to play with other children, and they will never know what the outside world is like.

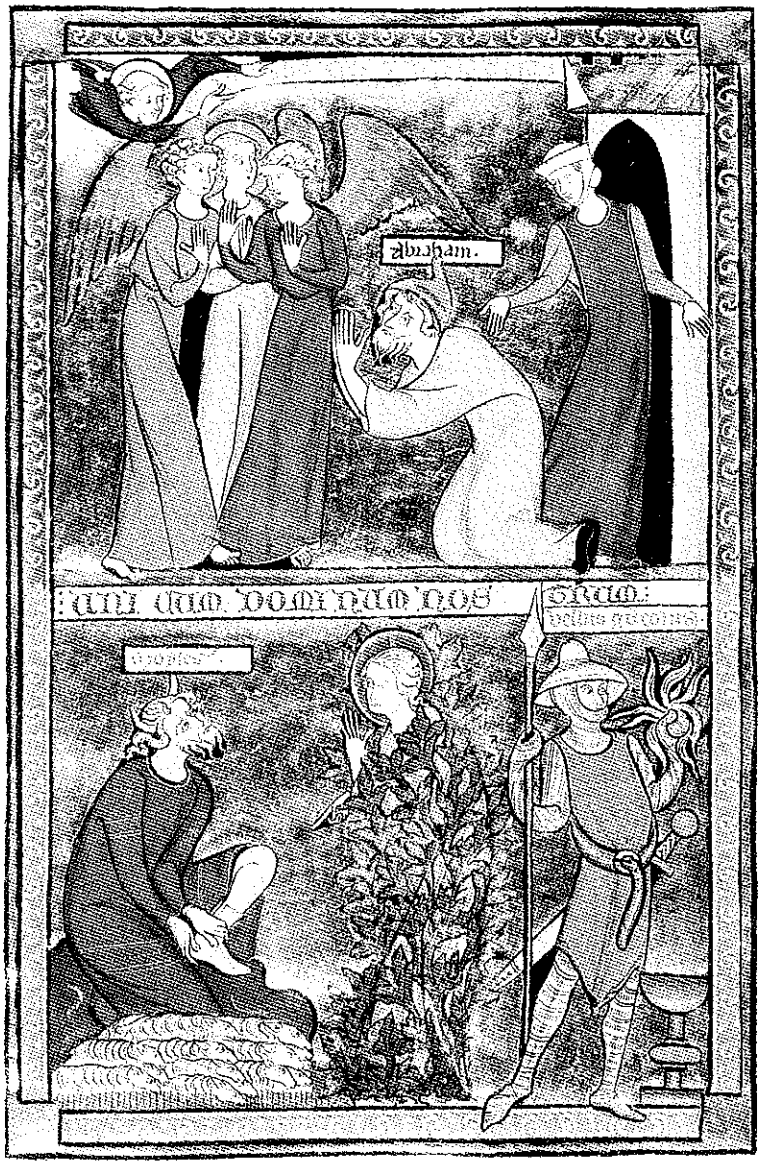
All they have before them is a cold, sterile world, in which all human relationships are impossible. They are fed by soulless mechanical arms. Total isolation—this is what lies before them, now and for the rest of their days.

Now, in the United States, with the aid of genetic therapy at a somatic level, one of these children has been allowed to escape from this terrible fate, and this is an encouraging success. What we have been able to achieve in this specific case may possibly be repeated in the future for other pathologies.

This shows the enormous potential of somatic level genetic therapy for many sufferers. But at the same time we are duty bound to consider the risks involved and prevent all abuse.

Statement of ethical responsibility

The risk of abuse creates a threat at a completely different level—we have to consider the possibility that modern genetic technology processes will in some way influence our scale of values. We already see



quite frequently that people are worried that new medical potential might once again stigmatize the handicapped within our society.

This is also dependent on the fact that western industrial societies have attributed constantly growing importance to medical prophylaxis, and the new genetic technology will enable us to further strengthen our defences against illness.

But people do not have the right to attribute to others personal responsibility for the handicapped because they did not take the new diagnostic potentials fully into account.

The use of genetic technology should, rather, take as its aim the simplification of the lives of the handicapped. In other words, maximum priority should be given to the recognition of personal dignity and the safeguarding of life.

Personal dignity

If, for example, parents decide to accept the risk of having a child that might be handicapped, we should not do everything possible to make them change their minds.

The decision is theirs and theirs alone, and our objective should be to reduce their suffering at all costs.

An acritical approach in suggesting and, above all, applying the new methodologies of prenatal diagnostics is not only contrary to the interests of the parents, but also, and above all, contrary to the

interests of the handicapped in our society.

For this reason, we must not accept any classification of genetic pathologies into categories. We cannot draw up a catalogue of illnesses and say, " We should carry out diagnostics for these ones but not for those ones. " And even more importantly, we cannot say, " When we see that there's something wrong, we should terminate the pregnancy. "

In Germany there has been considerable discussion on the possibilities and risks involved in genetic technology, especially with regard to human genetics.

The Federal Government and Lander agree that, on the basis of our legislative system, which allows the recognition of the uniqueness of and substantial differences characterizing each individual, legislative, ethical, and medical regulations should be drawn up as rapidly as possible which will be geared towards the principles of human dignity and the safeguarding of life.

The Federal Health Minister has done the preliminary work on this theme

International cooperation

However, laws at a national level are insufficient to exclude abuse.

We should reflect on whether it may be the duty of the community to establish general and binding ethical and legislative principles for the use of genetic methodologies on man.

The World Medical Association and the forthcoming European Council convention on bioethics have already prepared a number of preliminary studies in this sense.

The new Federal Lander: the improvement of living conditions

I am perfectly aware that, for some Eastern European representatives, the debates on this theme may seem extremely abstract. But these scientific discussions are necessary and vital, as they create new impulses for the work of the handicapped.

Certainly, the Eastern European nations are currently having to deal with quite different problems, and are only now beginning to deal with the question of the social integration of the handicapped.

In these countries, the first priority is the improvement of the conditions in which the handicapped live.

This situation also applies in East Germany, where the handicapped are left to their own devices as far as their daily needs and conflicts are concerned. They have no say in matters of public debate.

Not a word was spoken on the integration of the handicapped into society; if anything, the opposite was the case, in the sense that they were virtually exiled from society, especially if their condition was of a psychological nature. Associations for the handicapped were prohibited and no mutual aid was provided. The total and complete competence of the state was in no way linked to the principle of financial aid.

Only the churches offered the possibility of making an attempt to compensate for the failure of the state to provide for the handicapped.

We should not be surprised, then, if an attitude of tolerance, solidarity and humanity towards the handicapped emerges only with difficulty from such conditions.

The handicapped: their exclusion from society

We can clearly see the consequences of this situation, for example, in the way many of those who need aid and assistance live. Due to the very low number of outpatient facilities and short—and long—term hospital institutions, the handicapped were forced to live in centers that were totally inadequate for their requirements, such as psychiatric hospitals or homes for the aged.

And to this day, thousands of handicapped live in hospices and old people's homes!

Many centers for the treatment of the handicapped are totally obsolete and therefore incompatible both structurally and with regard to equipment. The physical structures of the buildings are often in catastrophic condition, sometimes beyond all hope of restoration.

Many of these centers are also tragically overcrowded and the standards of the institutions in the new federal Lander are in every case much lower than those in the Lander of the west.

We could take as an example the overcrowding of the wards, with 40-50% of patients sharing rooms with three or more beds. In such conditions, it is virtually impossible for a handicapped person to do any kind of work.

This situation is especially serious for the young, especially the mentally handicapped, currently living in psychiatric hospitals or homes for the aged. In Saxony alone, 7,400 new places are necessary, if we wish to create decent living conditions for these people.

For these reasons, the federal government, in the light of the community initiative known as *Aufschwung Ost* (Development of the East), is currently promoting above all the renovation and restructuring of hostels for the aged and geriatric assistance centers. It is clear, in fact, that the new Lander on their own are unable to guarantee sufficient assistance to those with serious disabilities and in need of help.

Another serious problem is the high degree of turnover in nursing staff. Many have moved to West Germany, where earning possibilities are higher, and for this reason we should express our sincere gratitude to the nursing and assistance personnel who have remained and continue to work in highly adverse conditions.

However, this does not change the fact that the shortage of staff increases the workload of the nursing and assistance staff, which in turn makes it impossible to fully implement the measures aimed at encouraging at least the chance of rehabilitation for the handicapped.

Objective: an independent life

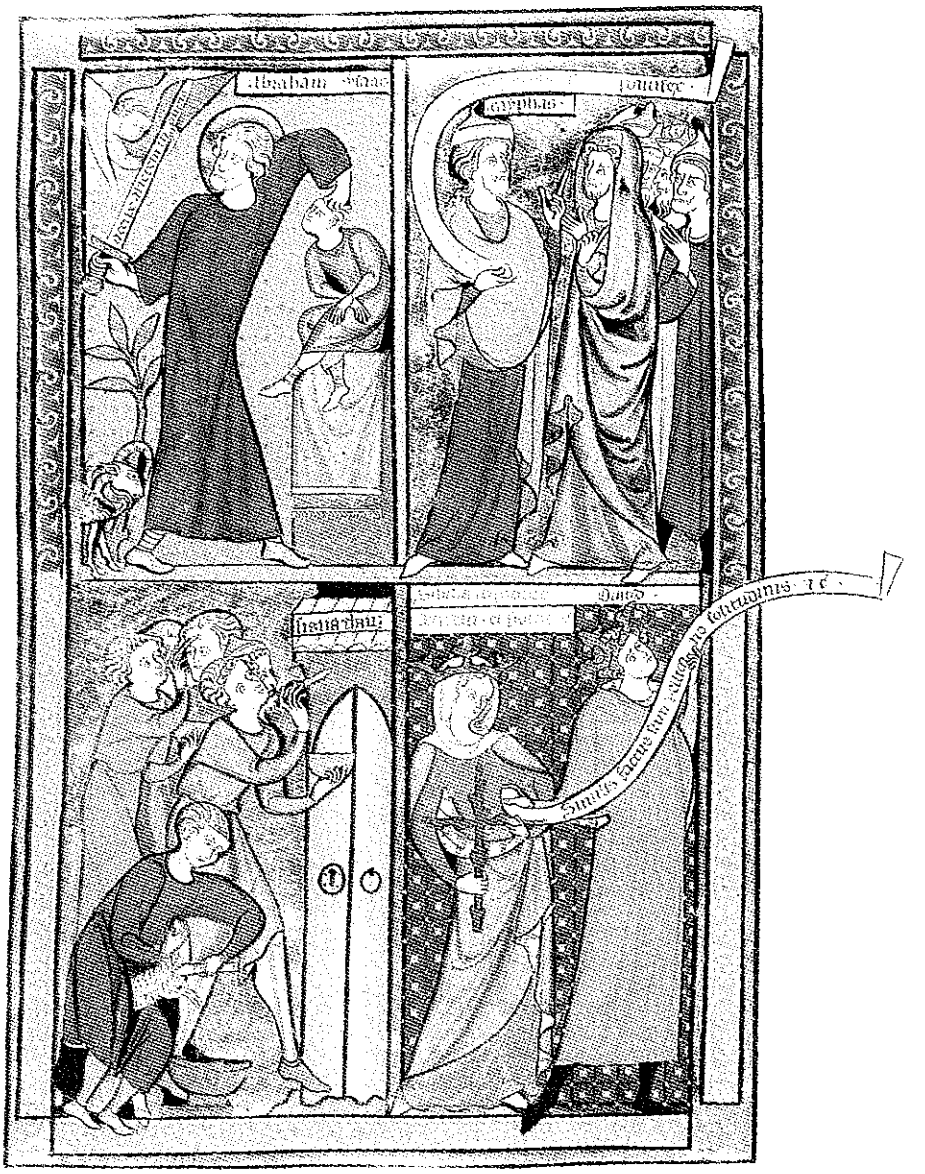
To be able to live independently in the outside world—this is the greatest ambition of many handicapped persons who continue to live in homes for the aged in East Germany. However, in many cases

this has been nothing more than Utopian thinking, because of unfavorable housing conditions, the shortage of outpatient services, and the presence of social factors, such as the high levels of female employment.

And even when families have decide to assist their disabled relatives at home, they have been given virtually no state assistance.

In the last two years the basis for home care has improved considerably. New mutual aid structures have been created all over the territory; local and regional charity organizations have been formed.

In cooperation with the voluntary associations, around 1,000 social units have been set up in the new federal Lander. These are working with many families in the field of home care, alongside the social services for outpatient assistence. The signs of change are encouraging.



Integration into working life

One of the most important conditions for the handicapped to take part in the life of society is the availability of work. For this reason, the Federal Republic of Germany recognizes the key role of professional rehabilitation. In the new Lander, this leads to quite extraordinary challenges.

As we know, in the ex-GDR, a job was provided for everyone who was capable of working, the handicapped included.

But now the situation has changed. In the market economy, no employer can be forced to appoint anyone. And many workers in the new federal Lander, in the light of the difficult economic situation, are against the employment of the handicapped.

We have seen, however, that even in this difficult situation good professional training is the best basis for the continuous integration into working life.

For this reason, professional consultants are now available in all the employment offices of the new Lander to deal specifically with the handicapped, who are offered special consultancy for the choice of a job followed by orientation towards company and noncompany training centers.

A special function in the professional integration of the handicapped in the new federal Lander is performed by specific centers (*Berufsforderungswerke*) for the professional reconversion of handicapped adults, and the professional training centers (*Berufsbildungswerke*), with basic training courses for the young handicapped.

Up to now, it is clear that the handicapped are making extensive use of the training and refresher course possibilities. This proves that even the handicapped are very eager to do as much as they can to guarantee social progress by means of their working contribution.

This is also the thinking behind the setting up of workshops and laboratories for the handicapped. These centers project the handicapped towards the world of employment and the professions in an active way.

These institutions, too, are seen by the handicapped as signs of positive change in attitudes towards them.

Medical rehabilitation

In spite of the major changes that have taken place since the fall of the Berlin wall in November 1989, the eastern part of Germany is still experiencing considerable difficulties in setting up medical rehabilitation facilities, as a consequence of the severe shortage of the special infrastructure necessary, es-

pecially for the sufferers of neurological pathologies.

There is a total lack of institutions where medical and professional rehabilitation can play a chain-reacting role between the specifically medical and professional rehabilitation phases. The creation of these structures is still at a very early stage.

Responsibility at every level of society

In the coming years, the prime objective of the rehabilitation policy of the Federal Republic of Germany will be to provide equal living opportunities for the handicapped throughout the country. And this is by no means an easy task.

But we cannot deny that many positive steps have been taken in the last three years for the handicapped:

— there is now a widespread state system of social guarantees to assist the handicapped to overcome or at least reduce their difficulties;

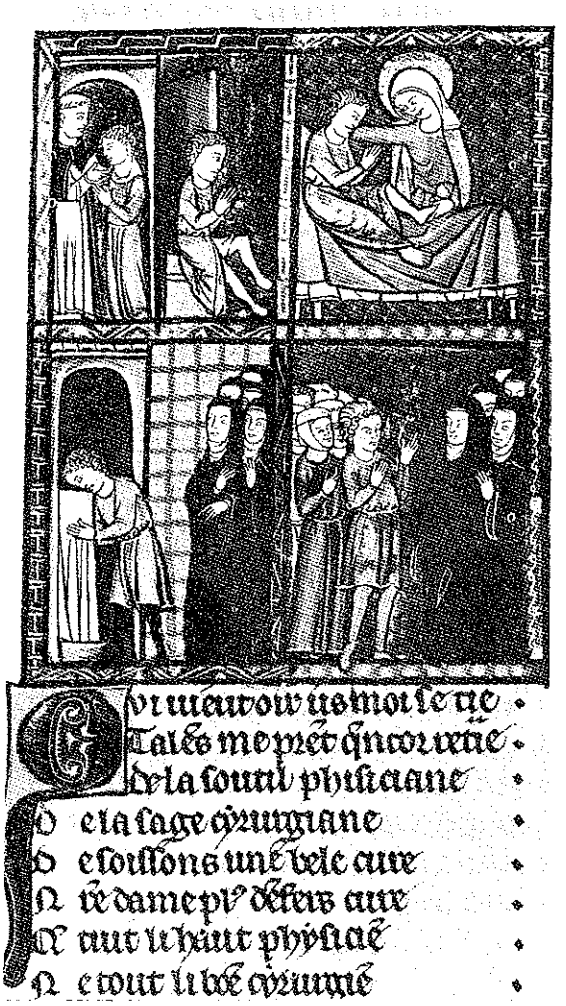
— the application of the legislative norms already in force in the old Lander has created the conditions for rapid and carefully aimed rehabilitation in the new regions;

— with the right to work (*Arbeitsforderungsrecht*) and the law on the bearers of severe handicaps, a versatile promotion tool has been introduced to ease the integration of the handicapped into working life.

If the handicapped are to take up their role in society, however, we have to do away with the prejudices and inadequacies typical of the last 40 years in the ex-GDR.

And this is the responsibility of society as a whole. Only when we have succeeded in fulfilling it will we be able to achieve our objective —the social integration of the handicapped.

Dr. SABINE BERGMANN-POHL
Member of Parliament and Secretary of State of the Federal Health Ministry



MARCO FRACCARO

Genetic Diagnosis: Past and Future

The great majority of genetic mutations cause handicaps. The evolution in the diagnosis of genetic illnesses has followed its counterpart in the field of genetic thought which, in its turn, has been conditioned by, and has become a stimulator of, advances in medico-biological technology. I would like to examine, briefly, what the evolution of genetic thought has been and then conclude with some reflections on the future, avoiding, therefore, the present. In this way I will escape the risk of engaging in that triumphalism which one should leave to certain circles which are involved in the subject and to certain organs of information.

I would like to avoid as well that easy game of tracing " pedigrees. " Such precedents often turn out to be such only with hindsight. Two examples may be cited of this practice. The well-known sculpture of 2,500 BC which depicts the dwarf Seneb, his wife Senetyotes, and their two children, certainly accurately describes a case of chondrodystrophic dwarfism, but it most emphatically does not do the same with regard to the hereditary character of skin color. The wish and often the anxiety to know the outcome of a pregnancy has always been present within us and is something which has frequently been exploited for ends which are far from edifying. A method by which males or females could be procreated, as presented in a Brussels publication, under the title *The Secrets of Reproduction* of 1837, merely amounted to some magical hocus-pocus. As we have recently discovered from certain newspapers, we can still find today, in the form of Grandmother Elda, its equivalents. The question, nonetheless, is of dramatic contemporary importance in those societies in which the birth of a female is seen to be a misfortune and the request to know the sex of the future baby—something which today can easily be granted, is directed towards avoiding such an event.

The era of modern genetics began with the publication in 1866 of Gregory Mendel's work. It sprang from that great center of culture which was the Augustinian monastery of Brno. The anecdotes about the lateness with which the Mandelian revolution created modern genetics shows, in addition, how scientific discoveries come to be applied and are recognized only when the development of scientific thought has reached a critical point. To give just one example,in August Weismann's monograph *Das Keimplasma* of 1892 we find that Mendel is not cited. We remember Weismann: fifty years later we can find him being accused of idealism and of being a corrupter of the Soviet Union!

The simple but brilliant observations of Archibald E. Garrod on " chemical individuality " and on hereditary transmission (published in *The Lancet* of 1902) were interpreted by Bateson, one of the discoverers of Mendel's laws, from whom Garrod had sought advice. Garrod's work is considered the starting point of human biochemical genetics, but many years had to pass before the first monograph appeared on the identification of the congenital defects in man's metabolism. Meanwhile, formal genetics developed through the study of the genetics of the vinegar fly. Today, going back to such studies with the techniques of molecular genetics, a start can be made on defining the mechanisms of embryo development.

For more than fifty years after Garrod, human genetics made no advances except with regard to the phenotypical definition of an ever-increasing number of genetic illnesses and in connection with the creation of statistical methods to assess their frequency and the probability of their reappearance within individual families.

In 1909, in *Essays in Eugenics*, Galton gave clear expression to his illusion of an improvement of the human species through selective breeding—a strange mixture of ingenuousness and mathemetical rigor. These ideas take on a sinister connotation only in retrospect, in the light of what happened in the late 1930s. In 1914, in *Zur Frage der Entstehung Maligner Tumoren*, Theodor Boveri attributed a decisive role to chromosome anomalies in tracing the origins of tumors—an idea that was contested ever after until the contemporary period, when it has gained acceptance. At this juncture we cannot forget that at the beginning of the 1930s there appeared works bearing sinister titles which were harbingers of subsequent tragic events. One such example was H.Gunther's monograph *Rassenkunde der Judischen Volkes*, published in Munich in 1931.

We can see that the first great advance in human genetics took place only in 1956. Two intermediate dates, however, should be remembered. First of all, there was the introduction, roundabout 1937, of the electrophoretic techniques of Arne Tiselius, which brought genetic mutations in man within the range of chemical analysis. Then there was the seemingly moderate but in reality revolutionary idea of J.D.Watson and F.H.C.Crick in 1953 regarding a new structure for DNA. But the application of the new molecular phase in genetic diagnosis would have to wait a number of years.

In 1953 Watson and Crick were convinced, like all the others, that man had forty-eight chromosomes, and, as a result of the combined application of certain simple tech-

niques, J.H. Tijo and A. Levan were able to see, at Lund in December 1955, the first exact representation of the forty-six human chromosomes. It had for long been suggested that certain genetic illnesses were caused by chromosome anomalies, but it was the great achievement of J. Lejeune to discover in 1958 that one of the most frequent and mysterious conditions was due to the presence of an additional chromosome—mongolism, as it was then known, the Down Syndrome, as it is termed today.

In this way the chromosome era began, and over the course of a number of years certain types (and their frequency) of numerous chromosomic anomalies came to be recognized and defined in precise terms. It should be remembered that in 1959, with E.L. Wollman's and F. Jacobs's monograph, *La Sexualite' des Bacteries* (Paris), important phenomena were described and defined which led on to the first modern ideas regarding the function of genes—I am referring here to the so-called sexuality of bacteria.

In 1960 two other major discoveries took place. Fifty years after Boveri, P.C. Nowell, and D.A. Hungerford identified, in their research in Philadelphia, a specific chromosome anomaly in a form of cancer—chronic myeloid leukemia. Today we know that this translocation displaces a gene and causes a tumor. The other discovery of 1960 was made by G. Barski and his team in relation to cellular hybrids—the fusion, that is to say, of two different cells to create one single cell. This discovery led, within a few years, to the use of artificial hybrids to identify and map human genes. Meanwhile, a start was made, albeit in approximate fashion, to map out these genes through the use of chromosome anomalies. At the same time, ten years after the work of Watson and Crick, there commenced research into the reproduction of DNA in chromosome anomalies.

The first number of the newsletter *The Human Gene Map*, which appeared in 1973 and was edited by V. McKusick, listed the few genes which had been mapped up till then. But at that time the application of the restriction enzymes and the Southern blot, which allowed from 1975 onwards the direct analysis of individual genes, was imminent. The advances in the identification of new genetic illnesses and in the mapping of genes were rapid: McKusick's catalogue *Mendelian Inheritance in Man* (Baltimore, 1966) tripled its size in the space of a few years.

I would like now to go back a little, to the year 1956. Human genetics gained its adulthood when in August of that year its first international conference was held at Copenhagen. As a young and enthusiastic participant, I sat in the front row whilst L. Sachs of the Weizman Institute expressed his views on the possibility of using liquid amniotic cells in the prenatal diagnosis of genetic illnesses. But neither I myself nor others present immediately followed this lead. Only twenty years later, in 1975, was there the first scientific conference on the subject. At that time the number of diagnostic amniocenteses carried out in Europe did not reach two thousand. The possibility of effecting a diagnosis of chromosome illnesses and certain genetic illnesses in the womb immediately gave rise to the dramatic dichotomy between the instinctive satisfaction of arriving at the stage of a diagnosis which had been sought for some time and the feeling that the prevention of genetic illnesses which had been diagnosed in this fashion could not come about except at the very high price of an induced abortion—we have not yet escaped from this dilemma.

In 1965 I had the chance to see a living ovule of a human female under the microscope which we were trying to examine to discover its meiotic chromosomes. This could have allowed the diagnosis of chromosome anomalies which did not otherwise lend themselves to diagnosis. At Cambridge, R.G. Edwards was studying the same things and within a few years had achieved the conception of what were called " test-tube babies. " In this way he gave the joy of having children to those who could not have them by natural means. What had been discovered was that gametes and embryos in their first stages could be manipulated with surprising ease. This led to the identification of various alternatives to natural reproduction but also gave rise to methods—and it would serve no good purpose to list them—which are repugnant to the consciences of many people, despite the fact that they have the common aim of obtaining a descent which would not otherwise be achievable. Using the famous title of François Jacob's book *The Possible and the Actual*, we can say that this is a field where there is a swift shortening of the time lag which in the scientific world usually arises between what is thought to be possible and its final achievement. It is also possible to engage the imagination in thinking about what might come about—something which should be done with full respect for scientific rigor. This was done by A. Lima de Faria in 1980 in his publication *How to Produce a Human with Three Chromosomes and a Thousand Primary Genes* (Hereditas, 1980). But today it is often clearly necessary to consider as belonging to the past that which only a few months earlier we thought belonged exclusively to the future.

In 1894 Thomas H. Huxley published a collection of essays under the title *Evolution and Ethics*. In reality, ethical problems are not new, whether they are those of 1894, suggested by Darwinian evolution, or those of today, which come under the heading of biomedical progress and are considered by numerous and varied committees. Such committees, unfortunately, are often composed of moral experts who are such only because they define themselves as such.

In conclusion, we have followed the development of genetic thought through an arbitrary selection of a series of dates. We do not know the precise dates of the Book. We do know, however, that many people, fortunately, look there for inspiration, not so much in order to solve what is contingent, but to draw from it constant comfort and guidance.

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JÉRÔME LEJEUNE

The Mentally Retarded: A New Approach

Mental retardation is one of the infirmities which is most characteristically human—only man can suffer from it. On the other hand, it is also the most inhuman because it deprives those who are afflicted by it of the most precious gift of nature—the full faculty of rational thought.

The example of trisomy 21 provides us with an opportunity to study the mechanisms of the dysfunction of the will at a practical level.

Children Affected by Trisomy 21

With their oblique eyes, small noses, and round faces with incompletely formed features, children affected by trisomy 21 seem smaller than other children. Every normal child has hands and fingers which are quite short; those of the trisomic child are especially so.

Their whole bodies seem rounded; there is no unevenness or rigidity. Their ligaments and their muscles have a certain looseness and this gives them a certain tenderness. This sweetness is also present in their characters. They are expansive and affectionate and exercise a special charm which is easier to perceive than to describe. This does not mean that trisomy 21 may be deemed a desirable condition. On the contrary, one is dealing with an implacable illness.

This combination of a tragic chromosome error and a really charming nature makes very clear what medicine actually is: hatred of the illness and love for the patient. What we have to do is to find out how these children should be treated and how the condition can be prevented.

The Symphony of Intelligence

The message of life carried by the chromosomes can be compared to a symphony—each musician (in our case each gene) does not play his part correctly if he does not follow the tempo of the orchestra.

During a solo a musician who plays too quickly (in the case of trisomy 21 the speed of a chemical reaction is too fast) can turn an andante into a prestissimo—the ears become too small, the fingers turn out to be too short. In contrary fashion (in the case of the absence of a chromosome the chemical reactions are less rapid), a musician who is behind will change an allegretto into a largo: the ear becomes too large, the fingers too tapered. In both these cases, the soloist deforms his own pieces without involving and ruining the whole symphony. But when the whole orchestra is playing, when each musician is taking part in a tutti, it does not matter whether one of the players increases or slows down in relation to the others. The result will always be a cacophony.

Human intelligence is indisputably the highest performance, the tutti of the genetic orchestra—it requires a harmony and synchrony among all of the different parts of the living organism.

It is certainly true that only certain genes amongst the thousands that bear the chromosome 21 are likely to produce this danger of an " overdose. " Indeed, if each gene were to cause such serious consequences even the survival of the embryo would be completely impossible.

It remains to discover which genes, amongst the thousands which are innocent, are responsible. This task is by no means easy—quite the contrary.

Chromosomic Regulation

We could save a great deal of time if we could monitor the action of a particular chromosome without disturbing the others. Let's make a simple comparison. A competent mechanic receives a four cylinder engine from the factory which by mistake has five sparkplugs. He immediately realizes that the engine does not work as it should do. An incompetent person would throw the engine away as scrap. But the expert carefully removes the superfluous sparkplug and makes the engine run properly. We, however—unfortunately—are not so wise as this astute mechanic. Luckily, nature is much more ingenious than we and knows perfectly how to eliminate one of the X chromosomes from women who possess two. For this reason our female companions do not have a crushing superiority over men with their sole X chromosome and small Y chromosome.

When will the moment come when we will be able to understand how nature really behaves? Will we, one day, be able to eliminate one of the three 21 chromosomes in our patients? For the moment, nobody can say. In waiting for that advance, what we must do now is patiently decode, gene by gene, the contents of chromosome 21.

A Biochemical Schema

The functioning of the brain implies that three main conditions have been fulfilled:

1) An enormous number of compounds must be present every eleven billion neurons.

2) A logical structure of astronomic length. Taking into account the dendrites and the axons, this lattice is at least five thousand kilometers in length. Calculated in neurotubules, which are probably the thin intraneuronal structure, this lattice would stretch from here to the moon and back!

3) A specific response of the "doors" though which the messages (the ionic canals) are introduced, and which must be opened or closed by the action of chemical mediators synthesized by the axon and which modify the ionic pumping of the membrane.

In seeking to satisfy these three fundamental needs, the brain must produce very considerable quantities:

a) of monocarbonaceous fragments for the preparation of chemical mediators (such as acetylcholine) or their secondary inhibition; for the preparation of the isolators (myelin); and for all the other transmethylation reactions;

b) of purine and pyramidine for the maintenance of the DNA and the enormous turnover of the RGA; this metabolism also requires the intake of monocarbonaceous residues in a highly oxidized state;

c) of tubulin for the stabilization of the neuronic grid and of bioprotein for the hydroxylation of the mediators.

It should be observed that the blocking of only one of these processes, of one of these metabolisms, can cause dysfunction with regard to intelligence.

Figure 1 summarizes these data. The column on the left represents the synthesis of purine. The column in the center does the same with regard to the metabolism of pyramidine (at the top) and purine (on the bottom). The column on the right represents the metabolism of the monocarbonaceous residues by means of tetraiodropholate (at the top) and the metabolism of the bioprotein and the hydroxylases (at the middle) and methylations (at the bottom).

The true amino acids, which supply an atom of carbon or are responsible for important metabolic stages, are placed within squares (on the right, on the left, and at the bottom).

On the far right are to be found the metabolic processes which lead to tubulin, the chemical mediators, and myelin. These three metabolisms correspond to the neuronal grid, the compounds, and the isolators which have already been described (Lejeune, 1990).

Genes of Chromosome 21

The first effect of the dose of the genes demonstrated in trisomy 21 was the excessive quantity of CuZn dependent superoxide dysmutase increased by a factor of 1.5 in the red cells of the patient (Sinet *et al.*, 1974).

The superoxide ion is transformed into H_2O. The oxygenized water, in turn, is transformed into H_2O by another enzyme—the peroxidase fluctuation, whose pseudogene is found on chromosome 21 (McBride *et al.*) while the principal gene is found on chromosome 3

Cystitionine Beta Synthetase (CBS)

The inaction of CBS leads to the accumulation of homocystine (which is not transformed because of the addition of serine and cystitionine). Homocystinic children are large and slim. Their fingers are tapered. This spider-fingered appearance is the opposite of the thickset appearance and stumpy fingers of children affected by the syndrome of trysomia 21.

This opposing effect, which is symptomatic of an anomaly of the homocystine, came to be explained ten years later by the localization of the gene (Skovby, 1985) on chromosome 21.

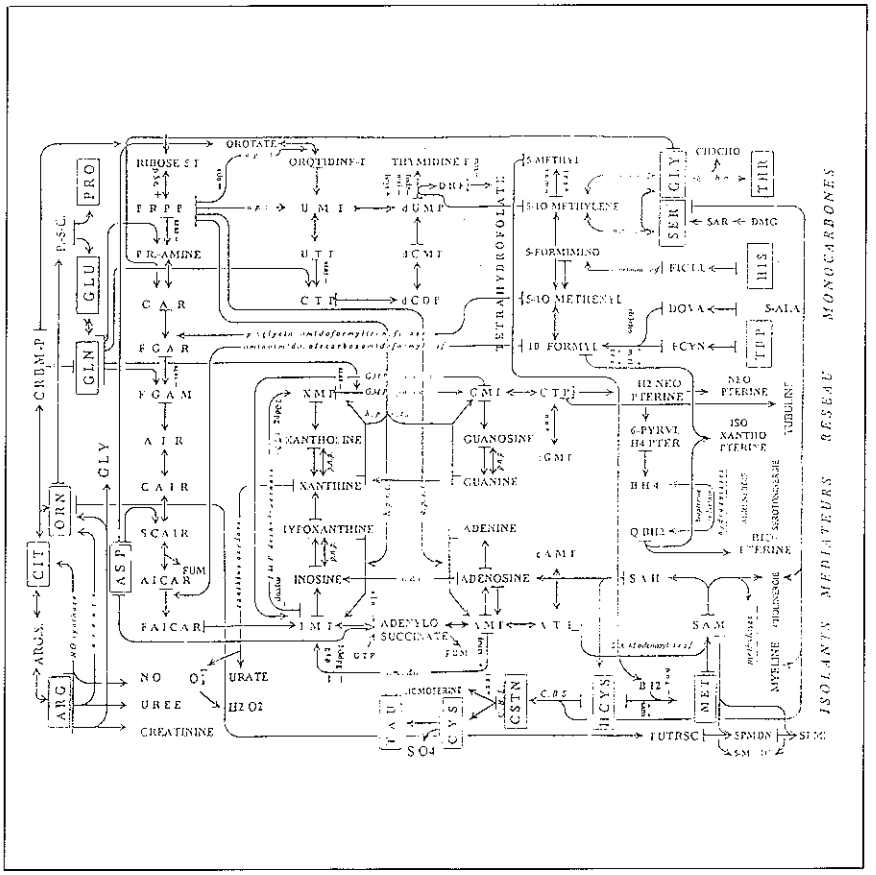


Figure 1: Model of Metabolism Essential to the Functioning of the Brain.

S 100 B

The S 100 B (Allore 1988) is a neuronal protein of particular importance, first and foremost in the hippocampus. It appears late in the back brain (Cicero *et al.*, 1972; Zuckerman *et al.*, 1970) and presents characteristics which are similar to the extension of the neurite (Klingman *et al.*, 1983).

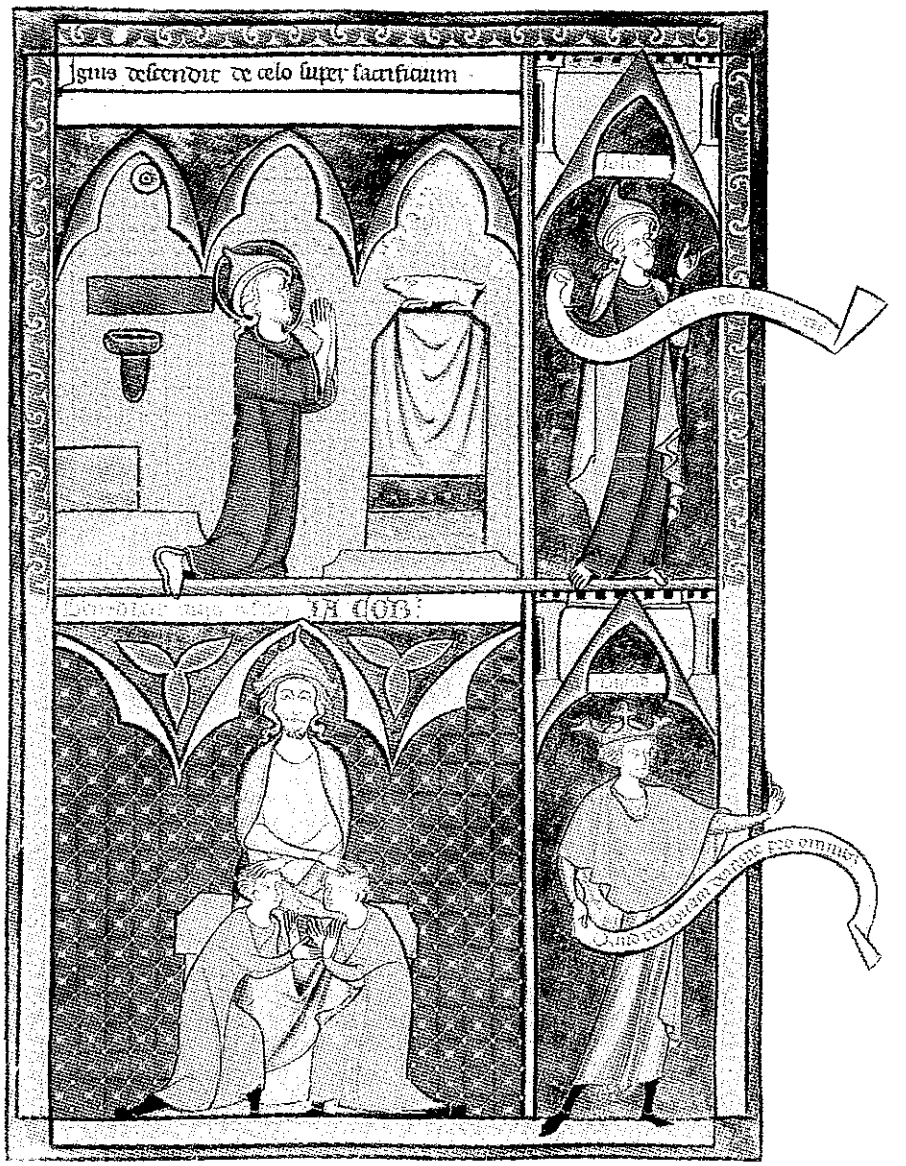
Phosphofructomutase

The excess of phosphofructomutase accelerates the synthesis of fructose-1,6-biphosphate. In this way the acetyl COA carboxylase is activated and accelerates the synthesis of lipids and perhaps leads to obesity. Given that the S 100 B protein has a particular affinity with the fructose-1,6-biophosphate aldolase 5 enzyme (Zimmer *et al.*), which enters the picture in the stage following the phosphofructomutase, it can be asked whether the localization of the genes does not perhaps correspond to a biochemical system.

Genes of the Purinic Synthesis and the Modulator Role of Adenosine

Excess of uric acid has been known about for a very long time (Fuller *et al.*, 1962; Pant *et al.*, 1968; Appleton *et al.*, 1970), and three genes are now localized on chromosome 21: the 5-phosphoribosyl-glycinamide synthesis (fig. 1 from PR amin to GAR), the formyl-transferase (from GAR to FGAR), and the amino-imidazole-synthesis (from FGAM to AIR). This acceleration increases the request for PRPP and thus of ribulose-5-P, produced by means of the monophosphate hexoses, whose GG-6PD activity is increased in the trisomy 21 syndrome (Sinet *et al.*, 1979). An imbalance of purine is important to such an extent that adenosine deaminase (fig. 1 ADA) and purine nucleoside phosphorylase (PNP) are increased in the akaryocytes (Pukka *et al.*, 1982) and in the lymphocytes (Pukka *et al.*, 1986), with an excess quantity of ADP (Stocchi et al., 1985; Magnani *et al.*, 1987), but not of ATP.

It could be that an excess of adenosine protects the person affected by trisomy 21 through its natural positive action from adenylocyclase succinate deficiency psychosis (Jaeken *et al.*, 1988, 1989), which leads to a deficiency with regard to the AICAR and AMP synthesis. The Lesh-Nihan pathology, another psychosis which involves terrible mutilations, causes a serious purinic deficiency because of the lack of hypoxanthine-guanine phosphoribosyl transferase (HPRT). A secondary deficiency of 10-formil-THF could come about, from which a destruction of AICAR (Pignero *et al.*, 1978) could follow. This last is the stage which follows the SCAIR (a product accumulated in the adenylocyclase succinate deficiency).



Precursor of the Substance B Amyloid

The substance called amyloid accumulates in the senile plaques in Alzheimer's disease (St. George-Hyslop *et al.*, 1987; Van Broeckoven *et al.*, 1987) and in certain angiopathies (Coria *et al.*, 1988) when there are disturbances of the thyroxine (Holmgren *et al.*, 1988) and in the case of dementia pugilistica as well (Heyman *et al.*, 1983; Roberts, 1988). This excess quantity is also to be found in trisomy 21. The gene of the protoprotein A4 is also present on chromosome 21 (Blanquet *et al.*, 1987; Goldgaber *et al.*, 1987) as it is in the case of a gene which is characteristic of the predisposition to Alzhe-

imer's. Nevertheless, an excess incidence of Alzheimer's syndrome is not present amongst the ancestors of children affected by the trisomy 21 syndrome (Berr *et al.*, 1989). Given that the first twenty-eight amino acids of A4 can form a polypeptide which promotes the survival of the pyramidal neurons of the hippocampus which are cultivated in vitro (Whitson *et al.*, 1989), the excess quantity of A4 could be a general symptom of an erroneous use.

Thyroid Dysfunction

Bournville was the first person, in 1906, to treat hypothyroidism present in patients already affected by trisomy 21 (Bourneville *et al.*, 1906). The frequent dual occurrence of the two pathologies led Benda to describe the presence of " thyroid exhaustion " in his patients (Benda, 1969).

In addition to an excessively high incidence of true hypothyroidism, from 1981 onwards (Samuel *et al.*, 1981) we have known about an excess of TSH (Lejeune *et al.*, 1988) accompanied by normal rates of T4 and T5. In 1988, with regard to a deficiency characteristic of rT3, the " inverse " or inactive hormone was described (Lejeune *et al.*, 1988) and then demonstrated in 1989 (Stoll *et al.*, 1989). The rT3/TSSH relationship, which has a high level of correlation with regard to T3 in normal people, does not display any correlation with regard to T3 in people affected by the trisomy 21 syndrome. It is as if the regulating system were modified (perhaps because of an overly rapid loss of iodine of rT3 in T2).

Metabolisms of Guanosine and Bioprotein

In finishing this biochemical excursion, it is necessary to stress the synthesis of tubulin, which utilizes GPT and is tightly controlled by the thyroid function (Nunez, 1985).

The fusion of the mitotic apparatus and the neurotubules (which, it appears, are the information network inside the neurons) are made of the same material—tubulin. A cell, therefore, has two possibilities to choose from:

the constant uniting and dividing of tubulin in order to multiply;

the final organization of tubulin in a permanent information network;

In the order of things, once the neurons have been differentiated, they no longer reproduce.

It is probably by no means a coincidence that the three pathologies which are characterized by a tangle of neurotubules are precisely trisomy 21, Alzheimer's disease, and hypothyroidism.

Biopterin, which is synthesized from GTP onwards and which is indispensable in the process of aromatic hydroxylation, is regulated in an anomalous fashion in people affected by the trisomy 21 syndrome. The level of BH4 is reduced (Hamon *et al.*, 1987) in the urine and the neopterin/biopterin ratio is high, as is the case of those suffering from Alzheimer's disease (Cottel *et al.*, 1989).

Sensitivity to Methotrexate

After the discovery by Peeters and collaborators in 1985 that children with trisomy 21 who had leukemia could not tolerate the usual therapeutic doses of methotrexate, the study of the metabolism of monocarbonaceous residues in trisomy 21 took on a very great importance.

In 1986 we demonstrated (Lejeune *et al.*, 1986) that the lymphocytes of trisomy 21 were twice as sensitive as normal lymphocytes when the methotrexate culture was applied.

The chromosomal fractures are even more frequent in this situation (Borghi *et al.*, 1987; Pels *et al.*, 1988).

The clinical sensitivity to methotrexate (Frankel *et al.*, 1986; Peeters *et al.*, 1986; Garre *et al.*, 1987) is fully demonstrated; to compensate, the pathways of the thymidine kinases come within normal levels (Peeters *et al.*, 1989).

All these data, when set beside the anomaly of the biopterin (see above) and the adenosine homocystine interaction, which has already been described at length, encourage research into a possible imbalance among the biosynthetic pathways which lead, on the one hand, to adenine and, on the other, to guanine.

There again, IMP dehydrogenase, which is a point of control of these two pathways, starting with inosine monophosphate (IMP), seems to be very carefully and effectively controlled (Peeters *et al.*, 1989).

A New Approach

This collection of data, which has already been accurately studied (cf. Lejeune 1991), enables us to have clear ideas about the future direction of our research. In concise terms, it may be observed that trisomy 21 involves a certain reduction in the hematic level of serine amino acid in these patients (Lejeune *et al.*, 1992). This deficiency is in line with the excessive activity of cystathionine-B-synthesase, with hypersensitivity to methotrexate and moderate reduction of methylation (see above).

It follows from this that hypochlenergy could be one of the three chief consequences of the damage caused by trisomy 21, in the same way as an imbalance in the purinic synthesis (through the guanine adenine pathways) could have the effect of situations of a psychotic kind. From the observation of slight improvements caused by moderate doses of L-methioine and of a probable beneficial effect of folic or folinic acid (Lejeune, 1991), the need has arisen to test systematically the greatest possible number of food additives:

the administration of folinic acid (donor of methylic groups),

the administration of inosine (precursor of purine) or guanosine (precursor of biopterin), of tubuline,

thyroid medical therapies in cases of thyroid deficiency.

The systematic study of the possible effects of such administrations is the subject of study and research which are currently underway

Conclusion

These reflections and observations, which tend to link trisomy 21 and its principal clinical symptoms with the imbalance of a certain metabolism of very great importance for the central nervous system, should not be seen as amounting to a declaration of victory.

Nothing and nobody can estimate how much we must still do before being able to reach the goal of all this research: improvement in the development of the intelligence of patients. As a consolation, I think it is right to reassure the relatives and families of our patients: the attempts of medicine are by no means without hope—in marked opposition to the views of those who would like to destroy those patients who have no chance of getting better.

Research is not exhausted and can be continued from now onwards without having to wait for the complete decoding of the entire human genetic inheritance, or even more simply that of chromosome 21.

It is not possible to say how much time will be needed before we will be able to deal effectively with the terrible consequences of an error in the workings of chromosomes, but one thing is certain: faced with the enormous difficulties of the task and the formidable need to succeed, we will never retreat.

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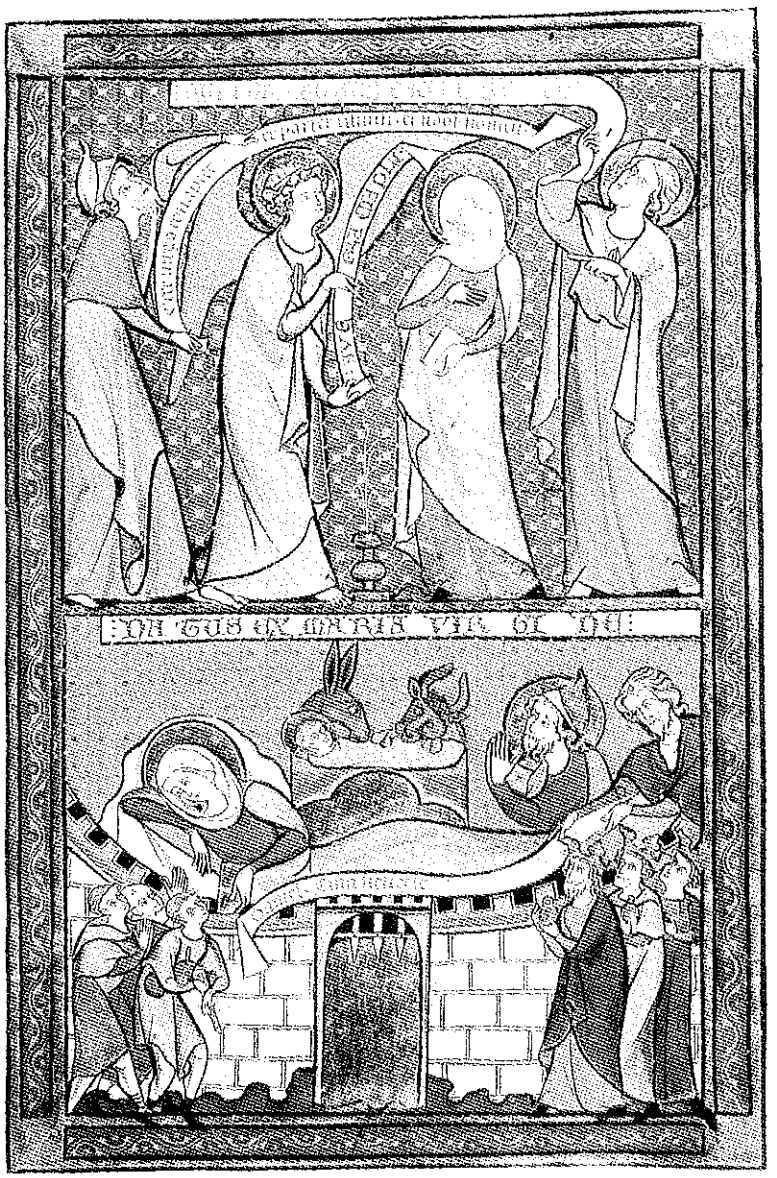

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RENATO DULBECCO

The Human Genome Project

Important causes of handicaps are diseases of genetic origin. Many of them are evident from the time of birth, but some, like Huntington's disease cases, develop only in adult age. We know several hundred hereditary diseases.

These diseases are caused by genetic alterations present in the germ cells and, therefore, in all cells of the body derived from them. They can be distinguished into three classes: mendelian, chromosomal, and multifactorial. The mendelian diseases, which are the majority of those known today, are caused by the alteration of some gene, often a change of a single base. The chromosomal diseases are caused by alterations, either of the number or the structure of some chromosome. For instance, the Down Syndrome is caused by trisomy in chromosome 21, and the syndrome of the cri du chat by a deletion in chromosome 5p. The diseases of multifactorial origin, that is, caused by more than one gene, are, so far, little known because it is difficult to identify the relevant genes. It is clear, however, that many congenital malformations, and many conditions, such as heart disease, hypertension, atherosclerosis, have such an origin.

The discovery of the genes responsible for hereditary disease was based, until recently, on two main approaches. One is cytology, the microscopic examination of the chromosomes in the affected individuals, using appropriate staining to visualize their bands. The goal is to find some visible abnormalities correlated with the expression of the disease. This approach is somewhat limited, because many hereditary diseases are not associated with visible chromosomal alterations. An approach of wider applicability is the study of families in which a disease is present, using probes that identify special DNA sequences, with the goal of finding some such sequence only in the diseased members of the family. The special sequences, known as polymorphisms, vary in different individuals without causing recognizable disease. Polymorphisms are recognized especially by using restriction endonucleases, the magic scissors that cut DNA at precisely defined points. Under the action of these enzymes, DNA is cut, giving rise to many characteristic fragments, the length of which can vary in different individuals. The variation is recognized by probes that recognize only one fragment out of the many thousand present. These probes were, until recently, obtained through accidental observations and are, therefore, in limited number. A correlation between a polymorphism and expression of disease shows that the gene responsible for the disease is in the proximity of the location of the polymorphism. However, such a proximity may still mean a distance of hundreds of thousands, or even millions, of bases. Therefore, starting from the polymorphism, the researcher may walk in the dark, looking for the gene. Such a search may last a long time and be very expensive. For instance, the discovery of the gene that causes cystic fibrosis took two years of work of two well-equipped laboratories, with a cost estimated at nearly one hundred million dollars.

These dificulties suggested a completely different approach for the discovery of genes, which led to the human genome project. This approach consists in establishing a map of the chromosomes, that is, a series of points of reference, on which a gene can then be discovered with much greater ease. This approach was made possible by two recent developments in molecular biology. One is the discovery of many magic scissors, the restriction endonucleases, which allow researchers to cut the DNA of a chromosome at specific points, generating characteristic fragments. The other is the possibility of cloning such fragments, by inserting them into vectors capable of multiplying in bacteria, yeast, or animal cells. The clones then allow the study of the characteristics of each fragment, using conventional techniques.

To generate a map, the DNA is cut by a restriction enzyme in such a way as to generate overlapping fragments. After cloning, the fragments are studied to detect the overlaps, by which they can be placed in the same order in which they are in the DNA. Thus the map is constituted by a series of overlapping clones covering the whole chromosome. It is equivalent to the map of a road, with the order of milestones and their distances. It does not tell anything about the genes, but it provides a framework in which a gene, identified by some physical feature, can be readily discovered.

The ease of generating a map depends on two factors: the size of the fragments that can be introduced into a vector, and the recognition of the overlaps. A major step has been the adoption of yeast chromosomes as vectors, because they can allow the cloning of frag-

ments of up to one or two million bases. They are called YACs (yeast artificial chromosomes). The vectors used before the YACs could accept fragments of no more than 50,000 bases, hence twenty times as many were needed to represent the same DNA length, with need for more personnel, higher costs, and slower progress.

For the recognition of overllaps, the approach of STS (sequence tagged sites) is now used. The STS are short sequences located at approximately equal distances on the chromosome. Their separation is such that several of them are included in the length of DNA carried by a large YAC. The STS are carried in the data bases, and physical segments corresponding to them can be easily produced in the laboratory. These are then used as probes to study a library of YACs. If two YACs react with the same STS probe, they must overlap.

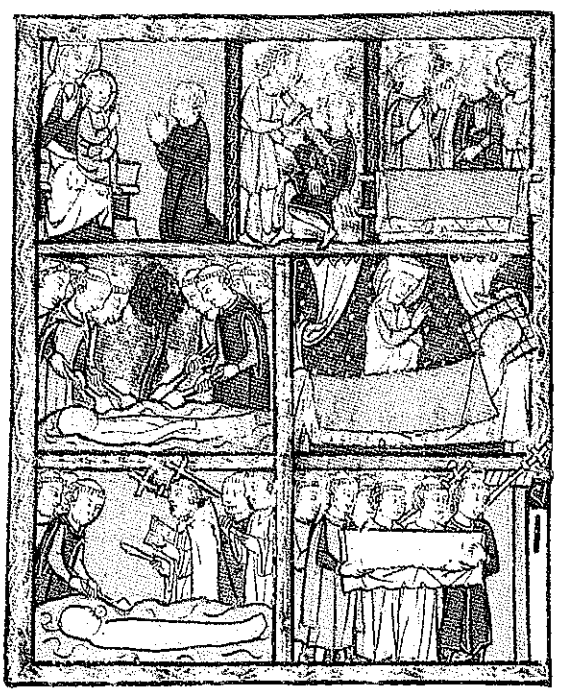
The effect of these technological developments has been dramatic. In fact, in the last month, the mapping of two human chromosomes using these approaches has been reported. They are chromosome 21 and the Y chromosome, which is characteristic of males. They are the two smallest chromosomes, and together they correspond to only two percent of the human genome. Moreover, the maps are not thought to be complete, or entirely accurate, for a variety of technical reasons. Nevetheless, this result has surprised everybody because it was not expected that mapping could proceed so rapidly.

The two chromosomes were mapped in two laboratories, chromosome 21 in Paris and the Y chromosome in Cambridge, Massachusetts. The amount of work was considerable. For chromosome 21, over 70,000 YACs were studied using 198 STS; for the Y chromosomes, over 10,000 YACs with 160 STS. In either case, large pools of YACs were first examined for their reaction with each STS, and then the constituents of positive pools were studied further. The final map of chromosome 21 contains 810 YACs and that of the Y chromosome, 234 YACs. These are the two most striking results, but many shorter segments of other chromosomes have also been mapped.

These results show that the mapping of the genome will proceed at a fast rate so that a complete map can be expected in a few years. It is, therefore, legitimate to ask what we can expect from the map. One result will be a much easier identification and isolation of genes, by studying the YACs in the regions defined by the family studies. The ease of identification of a gene responsible for a hereditary disease will depend on the type of alteration it carries. It will be easier if it carries a deletion. By studying the length of subfragments of the YACs obtained by appropriate restriction enzymes, it will be easier to identify the gene which includes the deletion because it will be shorter. In other cases, the identification will have to rely on the study of sequences by both direct and indirect methods.

An important question is what can be done once genes which cause hereditary defects are identified. The immediate result is knowledge, which can be used in at least two ways. One is for diagnostic purposes, to identify healthy carriers of the gene, if it is recessive, as most hereditary diseases are, or for prenatal diagnosis of disease. This knowledge can then be used for a program of genetic counseling in order to reduce the incidence of the disease. That this can be very effective is shown by the marked decrease it has caused in new cases of thalassemia in the Mediterranean basin. Another consequence is that the knowledge makes available tools for determining the effect of the genetic alteration, that is, the localization of the protein, its possible function, and the consequences of the alteration of the function. An example of this result can be seen with the cystic fibrosis gene.

The knowledge provided by the genes may also present problems of an ethical or moral nature. Thus, for genetic counseling, it is necessary to screen large numbers of people, with attendant high costs. This may make it impossible to have universal screening, but one limited only to the minority that can pay. Another difficulty is that, for effective counseling, it is necessary not only to identify the gene, but also to be able to recognize all its possible alterations causing disease. For large genes, which can be



altered at man sites, this is often imossible. In the case of cystic fibrosis, for instance, only about 90% of the changes are known. This means that some people could not know that they are carriers, and could generate a diseased child

Looking at the future, other possible consequences of the identification and isolation of genes for genetic defects can be foreseen in the area of therapy. We know today that it is possible to introduce a gene into cells where it will become established and will function, replacing the missing function of the cell's own gene. We know also that it is possible to make in the laboratory the so-called antisense RNAs, molecules that can greatly reduce the effect of a gene with damaging action. In the future, either technology may become the basis of therapy for some forms of genetic defects if applied either during fetal life or postnatally, depending on the effect of the effect of the alteration. Other therapeutic possibilities are based on the recognition that the function of every gene is performed by its product, which is, in almost all cases, a protein. It is either the lack of the protein or its wrong conformation that causes the genetic defect. A therapeutic goal for the future, therefore, will be the development of drugs capable of correcting or replacing the function of a given protein. A major obstacle here is the difficulty of determining or predicting the three-dimensional structure of a protein, which is responsible for its function. If this difficulty is overcome, this approach may become the major direction for correcting genetic diseases.

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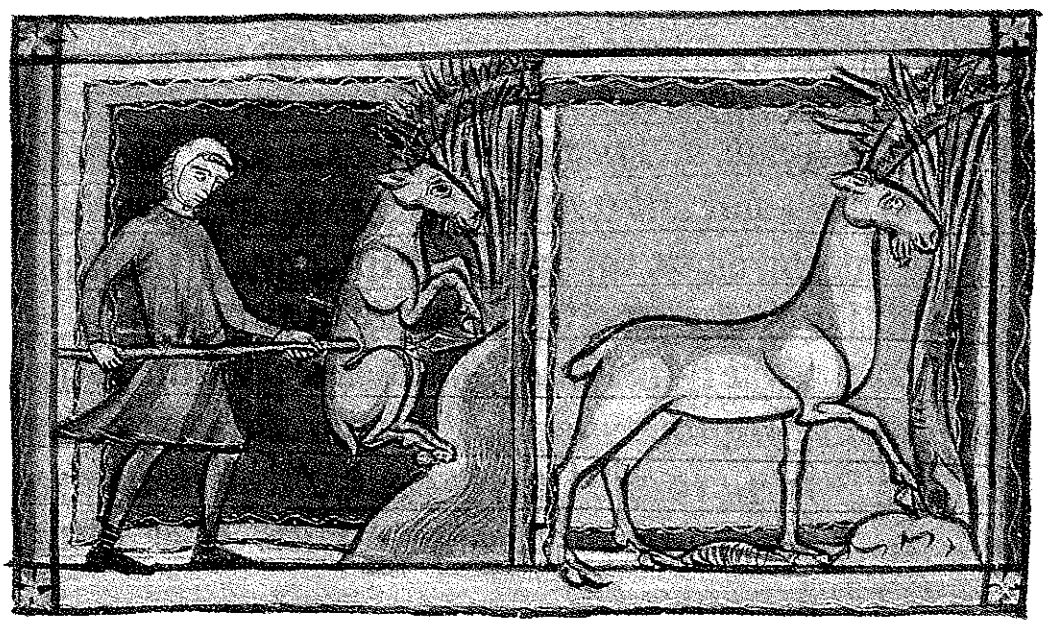


MARCELO E. CRUZ ET ALII

Malnutrition and Neurodevelopment Disabilities

To discuss malnutrition is to discuss world hunger, which affects, according to estimates of the United Nations Food and Agriculture Organization, up to 786 million people around the globe, while mean daily calorie availability per person has decreased from 2,900 to 2,290 in the last thirty years (FAO, 1992)

Death is the most serious complication of malnutrition, as we have witnessed in recent months in some African countries, where their populations actually starve to death 250,000 children die every week in the world for diet-related causes. International news media have broadcast images of horror, as thousands of children die in front of the television cameras, afflicted with profound nutritional disturbances that all of us thought were a thing of the past The worst drought of the century and civil unrest have been blamed for this inhumane phenomenon, but the international community has been rather slow in responding to implement famine relief efforts in the affected areas, and, worst of all, it is showing signs of " chronic fatigue " (Stone, 1992), in alleviating undernutrition in developing regions of the world, where millions of people are being deprived of the possibility of living a decent life. Malnutrition initiates a process of anatomical, physiological, and biochemical deterioration which, if maintained through generations, leads to a vicious cycle of decreased intellectual capacity and decreased work productivity The result is the formation of culturally isolated and economically marginal communities, where biological degradation induces human variability, amounting to social anthropophagia and vital regression, with virtual annhilation of entire ethnic groups, and where all hope for improvement is thus lost.

The object of this communication is precisely to review the scientific data that explain the dramatic situation that affects one out of every five human beings living on this planet (FAO, 1992).

Calorie Protein Malnutrition

Nutrition plays an essential role in fetal and neonatal development. There is overwhelming evidence to support the fact that maternal malnutrition induces not only neurological but physical defects in the developing fetus. The developing nervous system is vulnerable to gestational and lactational energy-protein malnutrition; not only neurodevelopmental disabilities, such as mental retardation and learning difficulties, but obvious birth defects can be traced to malnutrition in the mother (Cruz, 1991) Calorie-protein malnutrition during pregnancy may also contribute to an increased incidence of small-for-age neonates, prematurity, toxemia, and neonatal hypoglycemia All these conditions, per se, have been shown to be associated with an increased risk for selective learning disabilities and possible behavioral disorders The incidence of developmental disabilities in low-birth weight infants is significantly greater that in those of adequate birth weight, especially if it is associated with prematurity Characteristically, these infants are hyperactive and have a short attention span, deficits in comprehension and abstract reasoning, immature speech, learning difficulties, poor fine motor coordination, hyperreflexia, and an increased incidence of electroencephalographic abnormalities. A vast majority of children from developing countries suffer physical growth retardation as a result of malnutrition, and further deterioration of mental and physical health occurs due to recurrent infections and lack of sanitation.

The timing of malnutrition rather than the nutritional level may be more important in determining whether or not the deleterious effects of malnutrition are reversible. The peak period of human birth growth occurs during the fifth fetal month. In the postnatal period, a significant growth rate is maintained for a period of six months. The severity of the consequences of malnutrition depends on its timing in relationship to this vulnerable period of brain growth (late prenatal and early postnatal) The effects caused by prenatal protein malnutrition cannot be reversed from birth onward. Nutritional deprivation during early infancy, such as that occurring with marasmus, leads to drastic morphological and biochemical changes in the brain which are responsible for retarded human development. In addition to reducing brain size, the effects of malnutrition cause learning difficulties, decrease the individual's motivation, and alter his personality Severe protein-energy malnutrition, such as seen in both marasmus and kwashiorkor, impairs neurological and psychological functions during both the acute phase of the illness and during the immediate recovery period (Dodge, 1975). The central

issue is whether children who have sustained either acute or chronic malnutrition early in life retain permanent sequelae in nervous system function In the medical literature reviewed on this topic, mostly developmental tests have been used as means of assessing recovery (Barrera-Moncada, 1963; Cravioto and Robles, 1965; Pollitt and Granoff, 1967). The obvious subjective nature of these observations and the lack of adequate controls have limited their validity.

It is difficult to separate the effects of malnutrition from genetic factors, socioeconomic status, parental care, or a combination of these Child-raising practices and levels of prenatal care can significantly influence both the nutritional status and psychological development of the infant. Social and nutritional deprivation undoubtedly interact so as to modify the resulting behavioral characteristics (Manocha, 1972)

Moreover, in areas of the world where malnutrition is highly prevalent intestinal parasitosis is also endemic, specially in school children, further hampering their ability to learn (Crompton, 1988; Cooper and Bundy, 1987). Geohelminth infections freguently induce protein-energy malnutrition and iron deficiency anemia (Stephenson, 1987), which can interfere with attention in the classroom and secondarily with the learning process (Pollit, 1990, 1991).

At present, there is also ample evidence that malnutrition is a factor in poor response to infection. It is well known that malnourished individuals exposed to the measles or herpes simplex virus have a higher than expected mortality rate Cellular and humoral immunity is also altered in malnutrition. Depletion of lymphocytic populations and decreased ability to respond to tuberculin antigens or vaccination have been reported. Malnutrition compromises the host's response to infection. Therefore, it is not surprising to examine the reports on infant mortality, where a majority cases are linked to the concomitant presence of malnutrition

Iodine Deficiency Disorders

Iodine deficiency disorders are second only to calorie-protein malnutrition as a public health problem worldwide. In Latin America and the Caribbean alone it is estimated that 30 million persons are affected with endemic goiter. In this area also, another 250,000 individuals suffer from endemic cretinism, which is a syndrome consisting of mental deficiency together with neurological disorders (e. g., deafness-mutism, diplegia, and sguint), or endocrine disturbances such as hypothyroidism and stunted growth that has long been known to occur in areas of severe iodine deficiency, associated with endemic goiter. With improved socioeconomic conditions, this syndrome has now virtually disappeared from most regions of industrialized countries. However, it still persists in areas of high goiter endemicity in Asia, Oceania, South America, and Africa (Pharoah et al , 1980; Held et al., 1990; Stanbury, 1972; Stone, 1984; White, 1977), and in certain regions of Europe (Sguattrito, 1981)

Since the major CNS defects, manifested as various degrees of mental retardation, spastic diplegia, and deaf-mutism, are of prenatal onset, the term " Fetal Iodine Deficiency Disorders " (FIDD)

seems to be appropriate for the aforementioned neurological syndrome, rather than the old term of " endemic cretinism. "

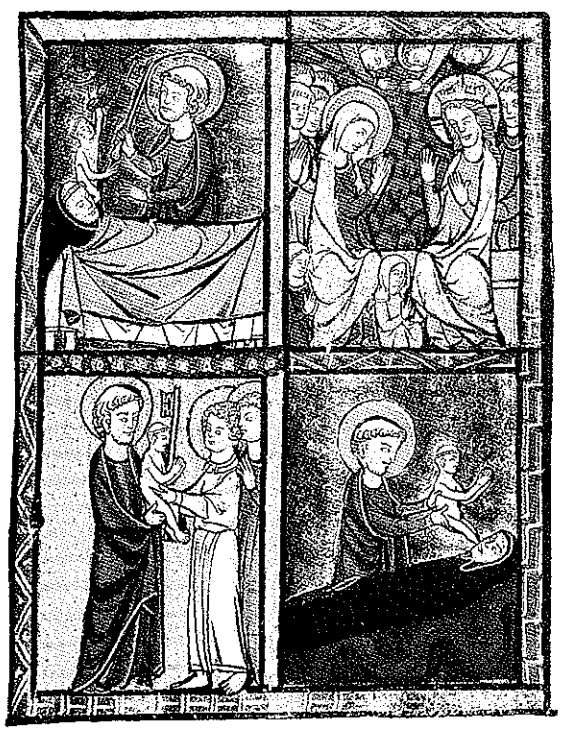
In iodine-deficient areas of the developing countries with high goiter endemicity, FIDD overshadows all other factors leading to mental retardation (Warkany, 1971; Cruz et al., 1978). In addition, it is probably the most significant etiologic factor for other neurological defects observed in these regions (Cruz et al., 1985). Neuroepidemiological studies conducted utilizing a standard protocol (Schoenberg, 1982) revealed that the neurological morbidity in an area with endemic goiter in highland Ecuador was surprisingly high, and specific conditions such as epilepsy, peripheral neuropathies, ataxias, language disorders, and extrapyramidal disorders were three- and fourfold as frequent as found in industrialized countries.

The concept of iodine deficiency as the prime cause of endemic goiter, endemic juvenile hypothyroidism, and FIDD has been widely accepted. Controlled trials in various geographic areas have shown that maternal iodine deficiency compromises the neurological development of the fetus and that these effects can be prevented by correcting the iodine deficiency prior to conception (Pharoah et al., 1980). Maternal iodine deficiency exerts its deleterious effects as early as the first trimester of pregnancy. The timing of the damage is before the fetal thyroid gland becomes functional (Pharoah and Connolly, 1987; Goslings et al, 1977; Morreale de Escobar, 1985, 1987). Though it was initially proposed that it was the lack of iodine itself which was responsible for the early damage in the fetus, from the results of clinical studies and animal experiments it is concluded that maternal hypothyroxinemia seems to be the decisive factor. As a consequence, before the onset of fetal thyroid secretion, the embryonic tissues become markedly deficient in T4. Since most of the T3 in the cerebral cortex is derived from local conversion of T4 to T3, this situation may be detrimental to the developing brain. In critical periods of brain development thyroid hormones affect neuronal cell differentiation by stimulation of growth and branching of the axon and dendrites. Thus, in maternal iodine deficiency because of low T3 levels, most likely cell proliferation of embryonic and fetal tissue is decreased. In the majority of fetuses this effect may be partially or completely reversible, whereas in a minority, having an autosomal recessively inherited genetic predisposition, this will lead to an irreversible nervous system defect. If the environmental stresses overwhelm the genetically-based adaptive capacity of the biologic system, IDD will continue to lead to the production of a deficit in individuals living in endemic areas, thereby compromising physical growth and neurological development in whole communities.

Data from 55 families with one or more affected probands from rural Ecuador were used recently to conduct a segregation analysis, trying to identify Mendelian traits. The probability (p) of any individual having a sibling as an affected proband was p = 0.26, closely corresponding to the expected segregation ratio of 0.25 for a presumed autosomal recessive inheritance (Held et al., 1986). The hypothesis of a simple mode of inheritance also predicts that the sequence of affected siblings is random. Analyzing the data of 50 informative siblings, no influence of birth order was determined. From the data available it was concluded that a genetic factor, e. g., an autosomal recessive gene, was necessary for the clinical expression of the fetal iodine deficiency disorder (Held et al., 1990).

In affected newborns, the pathologic process manifests itself as delayed myelinogenesis, and, clinically, as delayed acquisition of postural reflexes. In older children there is a specific syndrome, specially affecting the social, adaptive, and language spheres, consisting of excessive shyness, catatonic posturing, and communication difficulties (Delong, 1980, 1985).

The clinical picture of the adult affected by FIDD can be best categorized as a system degeneration that involves the descending supraspinal, ponto-reticular, and vestibulo-spinal tracts. Clinically, the affected individuals display a

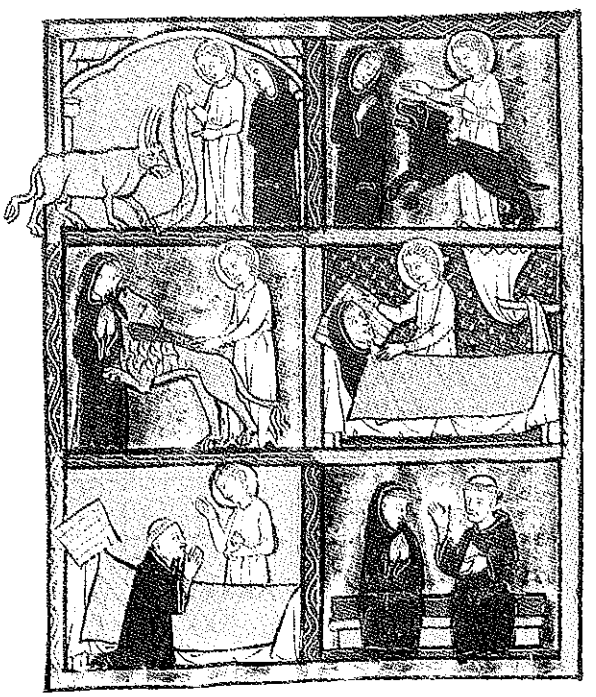


motor disorder that involves mainly proximal and axial movements and tone, with a flexion dystonia of trunk and extremities, and varying degrees of mental retardation. Affected adults develop early extrapyramidal and frontal lobe releasing signs, and show evidence of premature brain aging. Neurophysiological testing revealed EEG background abnormalities, as well as focal changes and paroxysmal discharges, signaling both cortical and subcortical disturbances. CT scanning has helped in the assessment of brain damage in patients with FIDD. The computed tomographic findings have been consistent with a severe ponto-mesencephalic atrophic process, probably secondary to degeneration of cortical and subcortical descending tracts. An associated cerebellar atrophy is also apparent, especially of the vermis and of the middle cerebellar peduncles, and there is a concomitant corticosubcortical atrophy (Cruz et al., 1984).

The geochemical modification of the soil environment generated by glaciation presents multiple covariates similar to that for iodine, which also affect other mineral components (Coyens et al., 1987). It has been postulated that such a mechanism may be involved in the pathogenesis of a proportion of extrapyramidal syndromes, related to ice-coverage during the last glaciation, as well as to altitude and rainfall (De Pedro, 1988). Therefore, an early life exposure to a geochemical imbalance, caused or aggravated by the last glaciation, could account for a high etiological fraction of neurological diseases in general in the high-Andean region, and may explain the unusually high morbidity found in the epidemiological surveys conducted in these areas (Cruz et al., 1985).

When these two clearly adverse factors, Calorie Protein Malnutrition and Iodine Deficiency, coexist, as they do in the high Andean region, the pathologic consequences are terrible and affect a considerable proportion of the rural communities, hampering their socioeconomic development.

Malnutrition, in the form of iron and vitamin A deficiencies, is causing serious disabilities, such as blindness, and the death of millions of human beings all around the world.



Behavioral and cognitive processes that may be affected by malnutrition and endemic infection were assessed with neuropsychological test procedures. The National Institute of Mental Health Attention Battery, developed at the Laboratory of Psychology and Psychopathology, was administered to an epidemiological sample of school children from San Pablo (N = 194, 9-13 years of age), a rural town in highland Ecuador, South America. The NIMH battery consists of a series of tests that measure verbal-visual ability, visual-motor efficiency, freedom from distraction, sustained attention or vigilance, ability to encode in memory, motor coordination, and level of flexibility to shift attention.

The following tests were applied by a local team of specially trained psychologists:

1. Peabody Picture Vocabulary Test, adaptation for Spanish speakers (Dunn, Padilla, Lugo, and Dunn, 1986).

2. Wechsler Intelligence Test, adaptation for Spanish speakers (1981), subtests: Arithmetic, Digit Span, Coding-digit Symbol, and Vocabulary.

3. Trail Making Test, adaptation of the original " Army Individual Test Battery " (1944), and Reitan (1986), intermediate and adult versions.

4. Stroop Test, Spanish adaptation of the three tasks: Words, Colors and Color-Word.

5. Digit Cancellation Test, with and without auditory interferences (NIMH).

6. Wechsler Memory Scale tests for automatic and numeric memory (Mental Control).

7. Motor Coordination Tapping and Rhythm Test (Kaplan).

8. Wisconsin Card Sorting Test (WCST, Heaton, 1981).

9. Continuous Performance Test (CPT), computerized version (Mir-

sky and Rosvold, 1956, 1981, 1991), which consists of three visual attention and one auditory attention subtests.

All the children were tested during the morning school hours, in an isolated classroom, specially prepared for the assessments.

Socioeconomic information on the family and anthropometric data were collected on all children by trained personnel, using standardized methods (United Nations, 1986). A neurologist performed a complete neurological examination on each child.

The exact ages of the children were ascertained from the local Civil Registry, which is considered the most reliable source. In the few cases where this source was incomplete, we used the school records.

Data were processed using the Systat 5.2.1 statistical package at the Laboratory of Psychology and Psychopathology, NIMH. The report of the results is based on t-test comparisons of arithmetic means, analysis of variance for group comparisons, linear regressions, and factor analysis. The level of statistical significance used was a two-tailed $p < 0.05$.

Results

There were 194 children, 97 boys and 97 girls; mean age was 126.84 months, SD 11.11 (range 103.66-155.36 months).

The children were classified into four groups according to the nutritional index based on the relationship height/age. The groups were: 1) normal nutrition, 2) mild malnutrition, 3) moderate malnutrition, and 4) severe malnutrition. Only 15 of the children were classified at the normal level of nutrition. The rest of the children was classified as follows: 24 mild, 37 moderate and 24 severe malnutrition levels. No statistically significant differences were found among the levels of nutrition in the comparison by gender and age.

Comparisons of the paternal and the maternal " number of years of education " across the four levels of nutrition were statistically significant ($F = 12.09$, $df = 173,3$, $p < 0.0000001$ for the father's education and $F = 18.47$, $df = 186,3$, $p < 0.0000001$ for the mother's education). The children of parents with more years of education belong to the highest nutritional groups.

The results of the Peabody Picture Vocabulary Test, which is considered a measure of verbal intellectual functioning, similar to the Wechsler Vocabulary subtest, indicated that boys and girls classified in the lower nutritional levels obtained the lowest scores in this test ($F = 20.94$, $df = 190,1$, $p < 0.00001$).

Gender Differences in the Neuropsychological Test Scores

The results showed statistically significant gender differences, with the girls scoring higher than the boys in all but one test across all ages.

On the Wechsler Coding Digit Symbol subtest, girls completed more symbols in less time and scored higher than boys ($t = -2.72$, $df = 191$, $p < 0.01$).

Girls scored higher than boys in two of the three forms of the Stroop Test, Stroop Color ($t = -2.21$, $df = 191$, $p < 0.03$); Stroop Color-Word ($t = -2.6$, $df = 191$, $p < 0.01$).

Girls scored higher than boys in the two forms of the Digit Cancellation Test, $t = -2.29$, $df = 155$, $p < 0.02$ for digit cancellation, and $t = -2.75$, $df = 168$, $p < 0.01$ for digit cancellation with auditory interference.

Two subtests of the CPT showed statistically significant differences in the gender comparisons: in the X-task (number of correct answers, $t = -2.38$, $df = 189$, p 0.02; and reaction time, $t = -1.98$, $df = 187$, $p < 0.05$) girls scored higher than boys; and in the auditory task (number of correct answers, $t = 2.11$, $df = 189$, $p < 0.04$ and number of omissions, $t = -2.13$, $df = 187$, $p < 0.03$) girls scored lower than boys.

Girls scored better than boys in the WCST, having fewer perseverative responses to stimuli, $t = -2.31$, $df = 183$, $p < 0.02$; girls also had more categories completed ($t =$

-2.52, df = 190, $p < 0.01$) and made fewer errors ($t = 2.84$, df = 183, $p < 0.005$). No other statistically significant differences were found.

Neuropsychological Performance and Nutritional Levels

The first step was to perform a factor analysis (principal axis) and learn which test scores are measuring similar cognitive abilities loading together on a factor. This analysis suggested a four-factor structure. The second step was to standardize and sum the test scores into four factors in order to condense the presentation of the data. The four grouped factors were the following: 1) vigilance and sustained attention, 2) freedom from distraction, 3) visual-motor efficiency, and 4) encoding. The third step was to analize the data further with linear regression procedures in order to search for a systematic relationship among the four levels of nutrition and the more coherent simple four-factor structure based on the individual scores from the neuropsychological tests.

Regression analysis results were statistically significant in three of the four factors as follows:

The scores in the " freedom from distraction " factor are in linear association with level of nutrition in boys and girls ($F = 7.04$, df = 191,1, $p < 0.01$), as are the scores in the " visual motor efficiency " factor ($F = 17.78$, df = 158,1, $p < 0.00004$), and the scores in the " encoding " factor ($F = 12.95$, df = 192,1, $p < 0.0004$).

In the three significant domains the data showed that girls performed consistently better than boys at all levels of nutrition. There was no statistically significant association between the " vigilance/sustained attention " factor (accuracy and reaction time scores) and levels of nutrition.

Discussion

The results indicate the existence of a close and systematic association among the nutritional levels of male and female school children in this population and their performance on neuropsychological testing.

Boys are more adversely affected by malnutrition than girls. Boys obtained lower scores in almost all tests, suggesting that they are more vulnerable than girls to the consequences of continuous malnutrition and endemic infection.

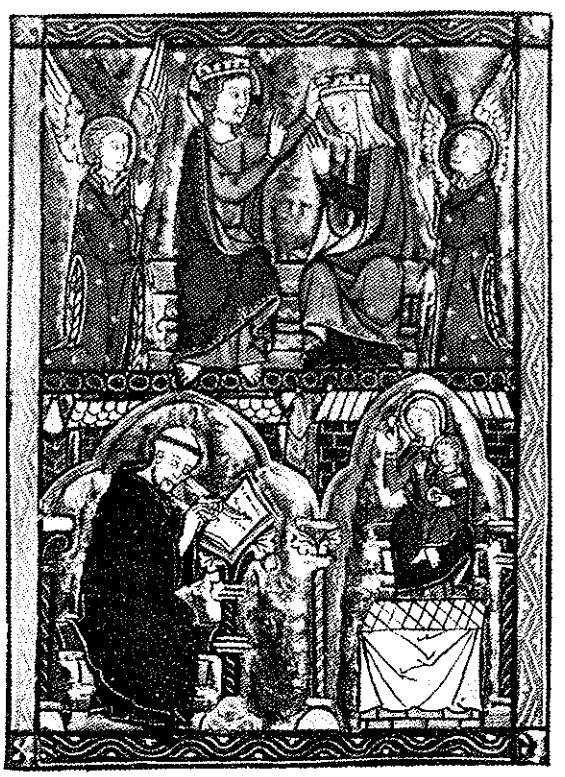
The cognitive functions assessed in the tests are directly linked to the general intellectual abilities required for normal performance in school age children. The age range of the children assessed in this study is crucial, since these are the formative years and optimal capacities are needed to succeed in the learning process in school.

Eighty-five percent of the children in this area are below the optimal level of nutrition and this status adversely affected, and will continue to affect their progress in all areas of functioning.

Maternal and paternal level of education has been recognized in the literature as an indicator of future school achievement and adequate development. In this study we can begin to specify the areas of neuropsychological functioning in which children are affected as a consequence of malnutrition during the most critical periods of life.

Of course, the countries where these limiting conditions are highly prevalent cannot blame only the outside world for their present situation. Their governments, our governments, systematically have chosen to sell foodstuffs to buy arms to defend themselves against imaginary enemies. We all know who the enemies are: they are illiteracy, lack of sanitation, malnutrition, parasitosis. Improvement in nutrition depends on economic development and guaranteed access to enough food of good quality.

Now that the East-West confrontation has been resolved, Humanity faces a new challenge: the North-South controversy. A better distribution of the world's wealth based on a profound solidarity among all nations will ensure that the newer generations will be free of disease and able to pursue happiness. This generation, unfortunately, is a lost generation for many countries in



the world. Let's all get together to improve the outlook of the future of the human race.

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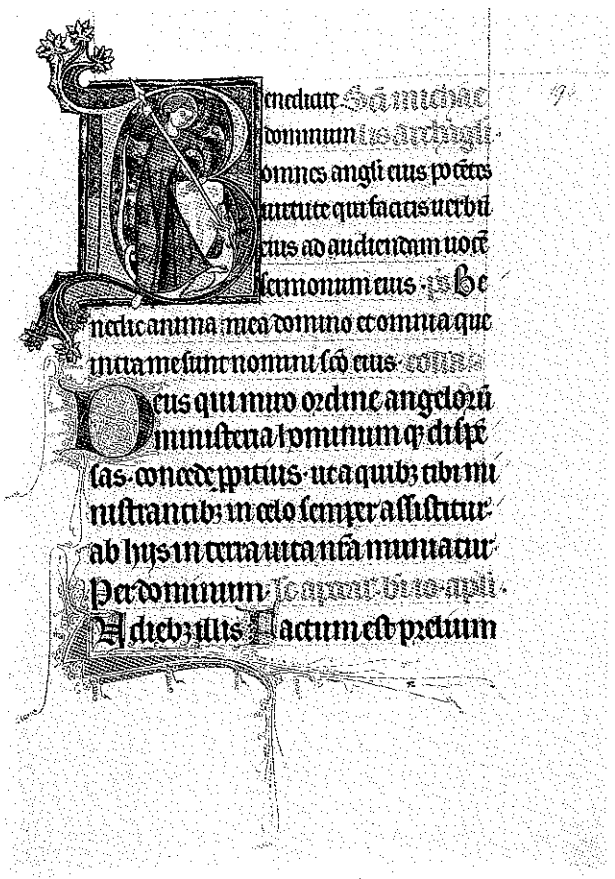

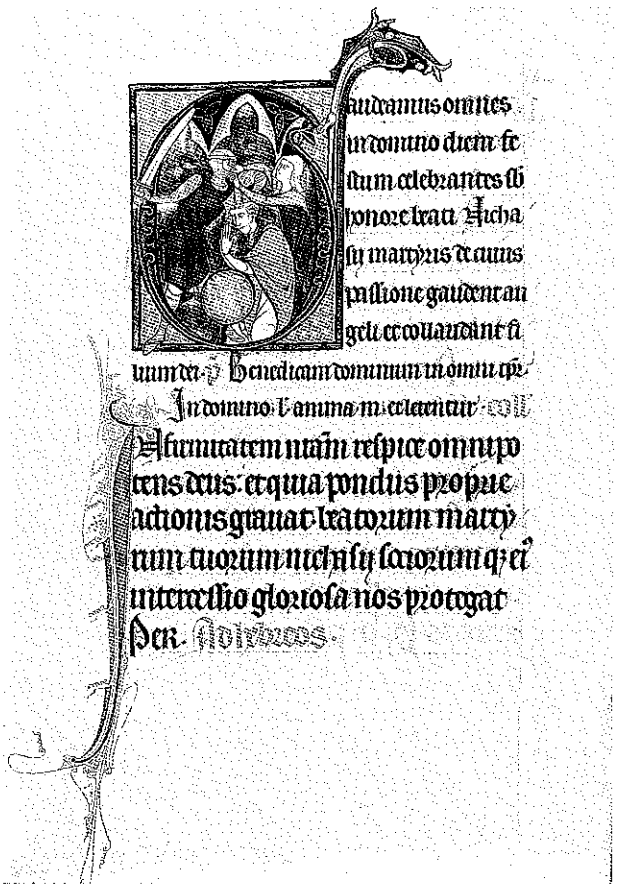

JULIUS AXELROD

Mental Illness, Drugs, and Neurotransmitters

Many afflictions of mankind are due to mental illnesses. The major mental illnesses are schizophrenia, depression, mania, anxiety, and drug abuse. These disorders inflict an enormous toll on the individuals with these conditions, disrupting their lives and those of their family. They involve great economic and social costs to society. There is also a stigma that is associated with mental illness.

In the United States more than two million people suffer from schizophrenia over the course of their lifetime. One out of ten Americans is affected by depressive or manic depressive disorder. Suicide is the third leading cause of death among young people between the ages of 15-24 years. Abuse of alcohol and drugs such as cocaine, heroin, and other mind-altering chemicals is prevalent. Almost all of us at some time or other experience anxiety, a feeling of uneasiness and apprehension. Many anxieties can be disabling. It is likely that a similar proportion of these afflictions is experienced by the rest of the world. In the past, there was little that could be done to effectively treat psychosis, severe depression, mania, or anxiety.

Early Studies on Drugs and Mental Illness

One of the early attempts to understand mental illness was made by the French physician Moreau de Tours (1804-1884). Moreau was trained by the psychiatrist Esquirol, who believed that one must love the mentally ill in order to be worthy of service to them. Moreau traveled a great deal and during his stay in the orient noted that hashish, a concentrated form of marijuana, which was in common use, had profound effects on behavior. He undertook a careful study of how hashish affected human behavior. Such a study, he believed, would give some insight into the nature of insanity. In his research Moreau described the symptoms of hashish as follows: first general feelings of pleasure, then increased excitement, distortions of dimensions of space and time, persecution, followed by mania, irresistible impulses, and hallucinations. These observations of the effects of a psychoactive compound on human behavior were one of the first carefully conducted scientific studies attempting to understand the causes and nature of mental illness.

More than 100 years later, in 1964, biochemists isolated the active principle of marijuana that affects behavior, and its chemical structure was characterized as delta-9-tetrahydrocannabinol. Recently, it was shown that cannabinoids (chemically known marijuana derivatives) can interact with structures called receptors on nerve membranes in specific brain areas. The cannabinoid receptor was identified last year by colleagues in my laboratory and shown to have a chemical configuration similar to other neurotransmitter ('brain chemicals) receptors. The normal presence of cannabinoid receptors on nerve membranes would imply that the brain has its own marijuana—like substance that influences behavior. There is an active search for these brain chemicals in many laboratories.

A drug that markedly affects behavior is cocaine. The cocaine-containing coca leaf was used by the Incas of Peru for their religious rituals and also served as a stimulant for heavy physical exertion. Cocaine was isolated from coca leaves, and its behavioral properties studied in the middle of the 19th century. One of the earliest investigations on the actions of cocaine was conducted by Sigmund Freud when he was a young neurologist. In 1884 he wrote to his fiancee about the actions of cocaine as fellows: " If all goes well, I will write an essay on cocaine, and I expect it will take its place in therapeutics by the side of morphine. I take very small doses of it regularly against depression and indigestion with the most brilliant success. " That year he wrote an article, " Uber Coca ", in which he claimed cocaine to be a safe exhilarant and recommended it as a treatment for morphine addiction. Freud's paper was severely criticized by the noted psychopharmacologist, Lewis Levin, who produced evidence that cocaine was not a substitute for morphine and that morphine addiction cannot be cured by cocaine. Levin did pioneering research on the physiological and behavioral effects of drugs such as cocaine, hashish, peyote (mescaline), and the intoxicating mushrooms (psilocybin) which he described in this book on psychopharmocology *Fantastica*. The action of cocaine on the nerves will be described below. Another investigator who studied the behavioral effect of drugs was Emil Kraeplin. In addition to his pharmacological research, Kraeplin was the first to describe disorders, which he named *dementia praecox*, that are now called schizophrenia. Symptoms of

schizophrenia, he found, began at an early age, were different from manic depressive illness, and showed a spectrum of behavior including thought disorders, paranoia, catatonia, and delusions

A chemical that induces abnormal effects on behavior is the ergot alkaloid lysergic acid diethylamide (LSD). When taken in tiny amounts, it causes bizarre behavior It was the Swiss chemist Alfred Hoffman who synthesized LSD in 1943. Hoffman ingested what he thought was a small amount of the compound, 0.25 milligrams, to examine the effects. After taking LSD he experienced distortion of vision, space, and time. His body seemed lifeless and without sensation. He thought he was going insane. Fortunately, he recovered after several hours. Because of its unusual behavioral effects, psychiatrists at first believed that LSD could serve as an experimental tool to study the nature of insanity. LSD was soon abandoned because of its unpredictable effects. It was later found that LSD interacted with serotonin-containing neurons in certain parts of the brain.

Another psychoactive drug is amphetamine, a derivative of adrenaline. Amphetamine was introduced in the 1930's to treat asthma. Because of its ability to produce euphoria and alertness this drug was widely abused. It was later shown to act by interfering with the actions of the neurotransmitter dopamine.

Discovery of Drugs to Treat Mental Illness

In the past, many forms of psychotherapy were tried to alleviate schizophrenia, depression, and mania, with little success. In the early 1950's, a quiet revolution took place in psychiatry with the introduction of drugs that showed promise in the treatment of schizophrenia, mania, and depression. The French surgeon Laborit noted that when he used the antihistamine chlorpromazine to prepare patients for surgery, it produced a " beautific quietude. " He suggested to his psychiatric colleagues that chlorpromazine might be used to treat psychiatric patients. When schizophrenic patients were given chlorpromazine, they became more manageable, and their' behavior improved Soon many similar drugs called neuraleptics were synthesized which were found to be more effective in treating schizophrenia and other psychiatric disorders.

Manic depression was another mental illness that was found to be treatable with the salt lithium. Manic depression is a disorder in which subjects undergo mood swings from manic elation and hyperactivity to hypoactivity and depression. Many historic figures were believed to suffer from manic depression, including Oliver Cromwell, Abraham Lincoln, Winston Churchill, Benjamin Franklin, and many famous artists and musicians. In 1949 an Australian psychiatrist by chance noted that when lithium salts were given to patients, they no longer experienced periods of manic depression. Lithium salts were soon introduced as an effective treatment for manic depression.

Most of us experience periods of depression because of some life event. However, some individuals suffer permanent depression and hopelessness, which sometimes leads to suicide. In the 1950's two kinds of drugs were found to overcome depression One was a monoamine oxidase inhibitor and the other was a group of chemicals called tricylics. It was observed that the drug isoniazide, which was used to treat tuberculosis, also elevated the mood of patients. These drugs were later found to relieve depression. These compounds were found to block the enzyme monoamine oxidase that disactivated a class of neurotransmitters called monoamines (noradrenaline, serotonin, and dopamine). While screening drugs for the treatment of schizophrenia, Swiss pharmacologists observed that trycylics were effective in the treatment of depressed patients.

The discovery of drugs that relieved schizophrenia, manic depression, and depression stimulated a search for a treatment for anxiety. A systematic search by chemists and pharmacologists led to the discovery of the antianxiety drugs valium and librium (benzodiazepines)

Another drug that served as a valuable tool to understand abnormal behavior and mental illness was reserpine. This drug is an extract of the plant *Ruwolfia serpentina* This plant was used in Hindu medicine for centuries to treat insomnia and insanity. In the early 1950's, reserpine was found to lower blood pressure in hypertensive patients. When taken in large amounts for a long periods of time, reserpine caused suicidal depression. Soon after, it was found that reserpine can markedly reduce the amount of the neurotransmitters noradrenaline, dopamine, and serotonin in the brain. About the same time it was found that amphetamine, when taken in large amounts, can induce symptoms of paranoid schizophrenia.

The ability of chemicals such as cannabinoids, cocaine, amphetamime, LSD, and reserpine to induce abnormal behavior indicated that there were biological roots to behavior. Almost all of these compounds resemble neurotransmitters in chemical structure. In addition, it was found by neuroscientists that drugs which relieve symptoms of schizophrenia, depression, and anxiety all interfere with the actions of neurotransmitters. Because neurotransmitters play an important role in inducing and treating mental illness, a description of what they

are, how they act, and how drugs influence them will be provided.

Neurotransmitters and Mental Illness

About 100 years ago, the Spanish anatomist Santiago Ramón y Cajal demonstrated that nerves are separated from one another by a space called a synapse. The billions of nerves in the brain talk to each other by chemical messengers called neurotransmitters that cross the synapse. Neurotransmitters are stored in vesicles at the nerve endings and, upon suitable stimulation, are discharged from the presynaptic nerve terminals. They then cross the synapse and are recognized by a receptor molecule at the adjacent post synaptic nerve or cell surface. (Fig. 1) Receptors have specific shapes so that the neurotransmitter fits into the receptor like a key in a lock. There are many types of neurotransmitters, such as monoamines (noradrenaline, dopamine, and serotonin), amino acids, and peptides. One neurotransmitter can be recognized by many kinds of receptors. For example, the neurotransmitter noradrenaline can interact with at least eight different receptors. Neurotransmitter release from the nerve can affect tissues of the body or the brain in many ways. They make the heart beat faster or slower and the muscles contract or relax. They can release hormones or act on genes. Neurotransmitters are agents through which the brain regulates movement and changes in mood and behavior. The interaction of neurotransmitters with their receptors generates chemical messages released to the interior of a nerve or cell. These messages then stimulate a complex cascade of biochemical reactions so that nerves or cells can carry out their special functions.

About 30 years ago, with my colleagues and coworkers, I had the opportunity to show how drugs that relieve depression affect neurotransmitters. We had previously discovered a mechanism by which the action of the neurotransmitter noradrenaline was interrupted by recapture or uptake by presynaptic nerve endings after it was released. (Fig. 1) It was later shown that

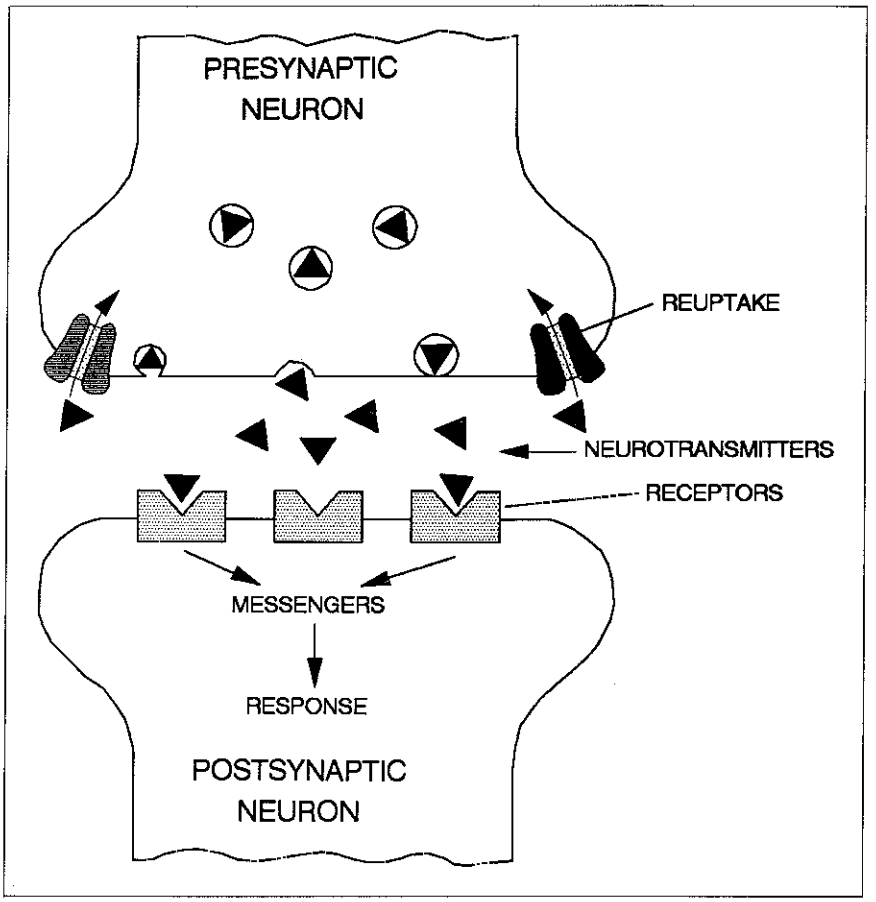

Figure 1. Storage release and inactivation of neurotransmitters in the nerve synapse

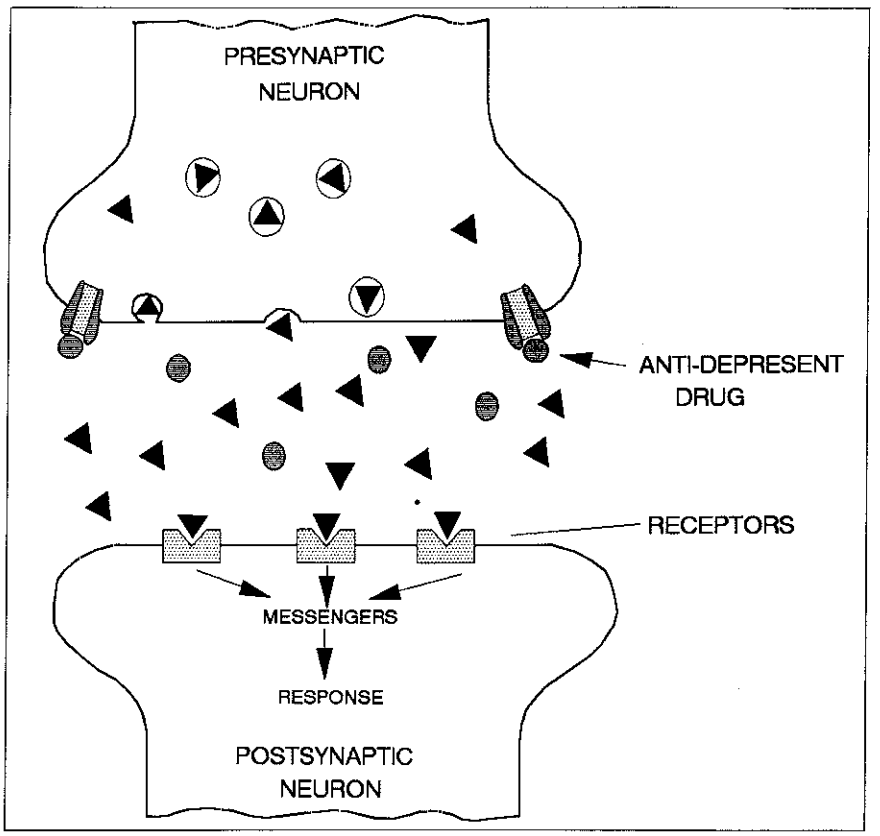

Figure 2. Antidepressant drug blocks uptake of neurotransmitters.

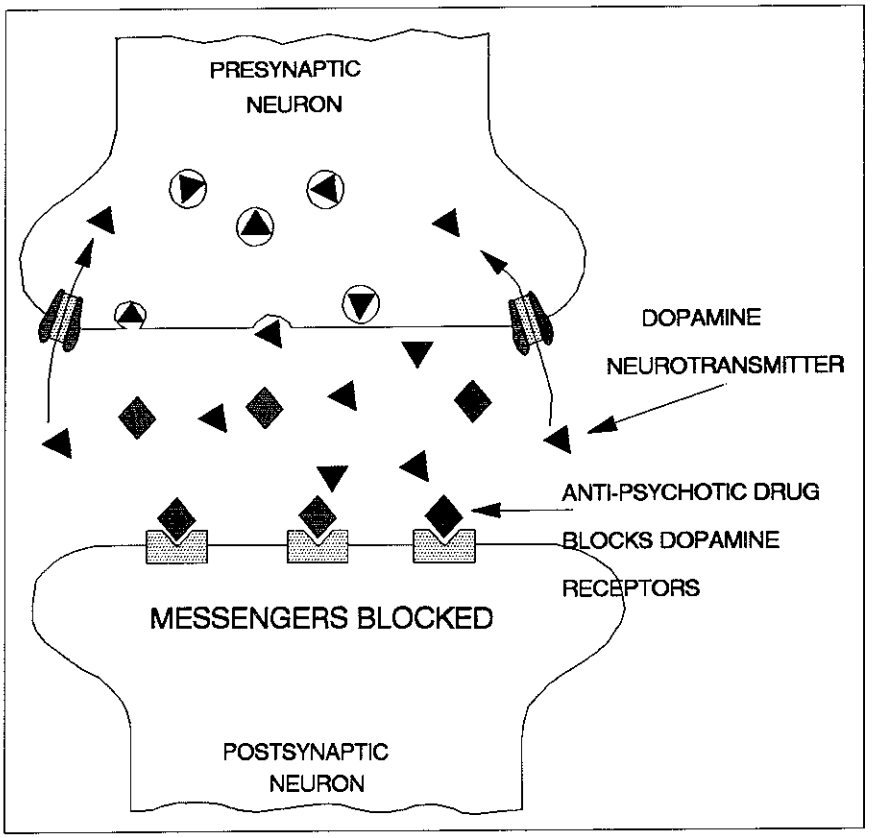

Figure 3 Antipsychotic drugs block postsynaptic dopamine receptors

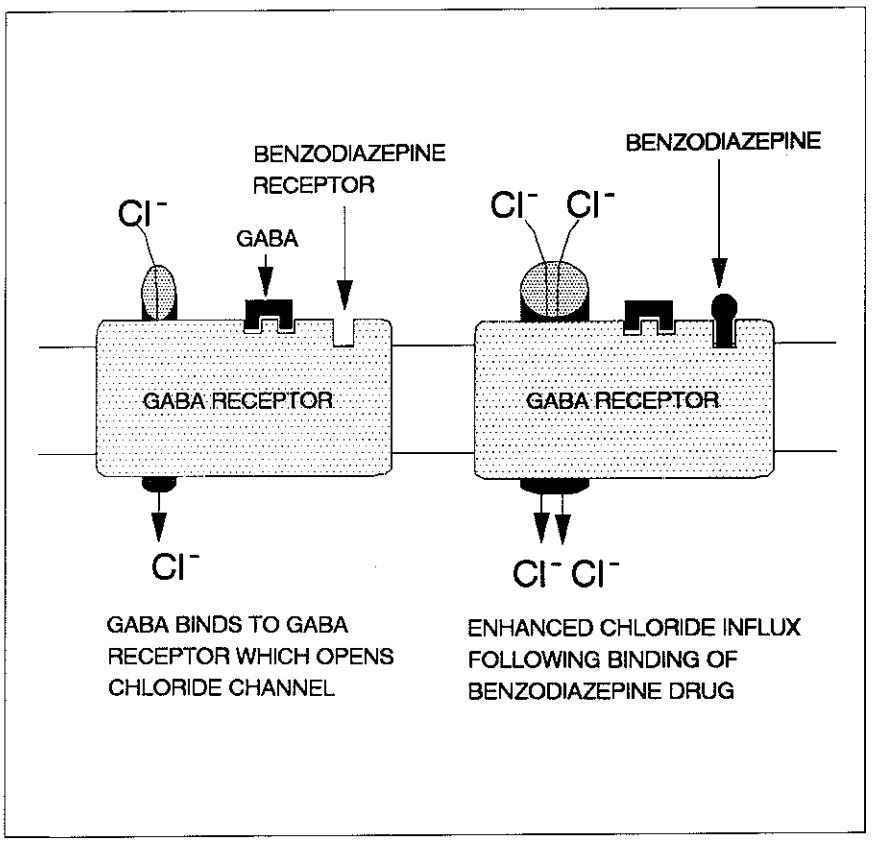

Figure 4. Antianxiety drugs enhyance the actions of Gaba receptors.

almost all neurotransmitters were disactivated by uptake in presynaptic nerves. Knowing this, we were in a good position to examine how psychoactive drugs influence the uptake and release of noradrenaline.

The first compound we studied was cocaine, a potent stimulant that can induce euphoria and psychosis. In our experiments with cocaine, we found that when animals were given cocaine, the uptake of noradrenaline by nerve endings was prevented. By doing this, cocaine magnified the effects of noradrenaline by preventing its recapture by nerve endings, leaving larger amounts of the neurotransmitter in the synapse. This would intensify the effects of noradrenaline and, in an as yet undetermined manner, influence behavior. In another series of experiments it was found that a class of drugs called triylics, that relieved depression, also affected the uptake of the neurotransmitters noradrenaline, dopamine, and serotonln. (Fig. 2) Monoamine oxidase inhibitors, drugs that relieve depression, prevented the metabolism of noradrenaline, dopamine, and serotonin. Although these drugs alleviate depression by different mechanisms, they increase the amount of neurotransmitters in the synapse so that more of these brain chemicals are available to interact with their respective receptors on neighboring nerves. Amphetamine causes the release of dopamine and also blocks its uptake, which induces paranoid behavior. Reserpine is a compound which, when taken in large amounts, reduces the amount of neurotransmitters in nerves and can sometimes causes suicidal depression.

The introduction of drugs to treat psychosis in the 1950's revolutionized the treatment of schizophrenia. These antipsychotic drugs markedly reduced the stay of patients in mental hospitals. The observation that these drugs can relieve the symptoms of psychosis in schizophrenia led to a search by pharmacologists to find out how they exert their action in the brain. In the 1960's, it was observed by the Swedish pharmacologist Carlsson that antipsychotic drugs affect the neurotransmitter dopamine. Snyder and his coworkers then found a strong association between

the ability of anitpsychotic drugs to block dopamine receptors and their ability to relieve schizophrenic symptoms. (Fig. 3) It was later found that there were two families of dopamine receptors, one which stimulates neurons and another which inhibits neurons in certain areas of the brain. Drugs that are effective in treating schizophrenia were found to recognize dopamine receptors that inhibit neural activity. Recently, the chemical structure of both the stimulatory and inhibitory dopamine receptors has been characterized. This information should lead to the development of drugs that relieve schizophrenic symptoms without producing the neurological side effects that often occur with the longterm administration of these drugs to patients

Most people, at some time or other, have feelings of anxiety, vague dissatisfaction, and discomfort. Many others have excessive feelings of anxiety with marked apprehension, irratibility, distress, and physical symptoms, with no apparent reason. In many cases they resort to psychotherapy to treat their anxiety. Psychotherapy may help some people, but most remain just as anxious. In 1960 benzodiazepine drugs were developed by chemists and pharmacologists which were found to relieve symptoms of anxiety. Although benzodiazepines were effective in relieving anxiety, they became excessively used for minor distress and to help people cope with everyday life. Like many other drugs for the treatment of mental disorders, benzodiazepines exert their action on neurotransmitters. The neurotransmitter upon which benzodiazepines act is gamma aminobutyric acid (GABA). About 15 years ago it was observed that benzodiazepines recognized and bound to GABA receptors. Neuroscientists meanwhile had found that GABA—containing nerves inhibited nerve activity. Some years later the complex chemical structure of GABA receptors was elucidated. It was found that when the antianxiety benzodiazepines bound to GABA receptors, they increased the inhibitory effects of GABA neurons. (Fig. 4)

The discovery of drugs that can alleviate mania, depression, schizophrenia, and anxiety indicated that these mental disorders have biological causes. These drugs have also had an important impact on psychiatry, creating the new discipline of biological psychiatry. It provides a valuable framework for an experimental approach to the study of schizophrenia, mania, depression, and anxiety. This has led to the introduction of safer and more effective drugs and a better understanding of the treatment of mental illness. These drugs have also provided valuable tools to illuminate the function of the brain. In spite of these advances, much has yet to be done to understand and treat mental illness.

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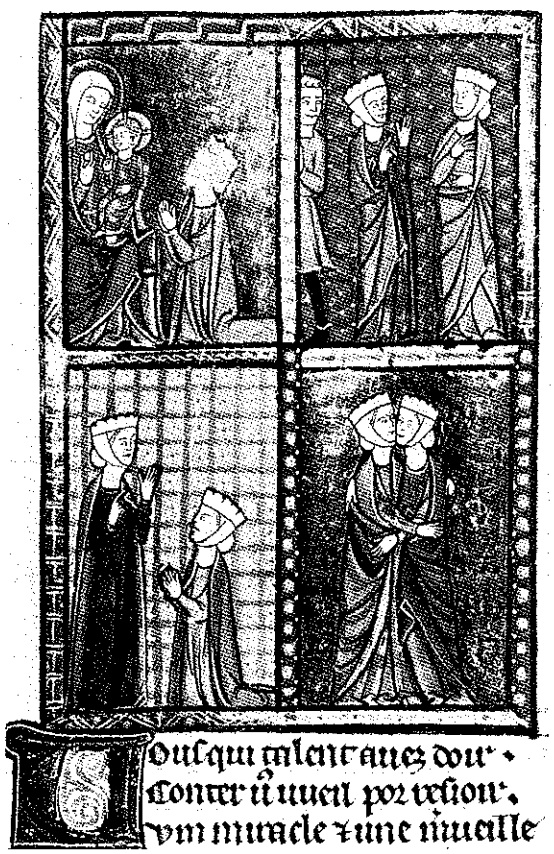

L.S. SCHLACK POBLETE

Physical Disturbance in Development

It is unusual for the " physical handicap " of a child to be pure in form. It more often takes the form of an overall deficiency in which a physical limitation prevails, for example, of a motor, neurological, or malformational character. Given that the same damage which causes the physical problem can also affect the central nervous system, it frequently happens that in addition to the physical impediment of the child there are other deficiencies, such as disturbances of the cognitive processes, sensorial problems, retarded language capacities, or disturbances of socialization. It also happens that the physical limitation is itself a cause, in turn, of secondary deficiencies in other organs.

Amongst the most important physical disabilities are to be found such syndromes as cerebral paralysis, meningocele, hydrocephaly, muscular illnesses due to various causes, infection of the central nervous system, achondroplasia, traumatic consequences such as the polytraumatisms resulting from traffic accidents, neurofibromatoses, and the secondary damage caused by tumors of the central nervous system, and so forth.

An important part of the abovementioned sequences can be avoided through suitable care during pregnancy and at birth, rigorous attention to the new born child, proper medical attention, and the timely diagnosis of infections of the central nervous system and of metabolic illnesses or endocrinal disturbances, such as phenylketonuria, hypothyroidism, or mitochondria. The great advances in the field of care for the new born child have enabled us to avoid a whole host of physical limitations. However, the very advance of medicine has involved the challenge of diagnosing and rehabilitating an ever greater number of disabled children—premature or malformed children who years ago would have died. Early diagnosis and the survival of many children who have limitations put the professional health care worker at the forefront in the search to find for the child and his family a satisfying quality of life and to reduce the impact that the deficit frequently causes in the familial, educational, and work or professional spheres.

Clinical Aspects

The physical disability of a child still at the milk stage or of a pre-school infant is reflected in the development of a majority of their psychic and neurological functions, which, at this stage of life, proceed at greater speed. A purely motor deficit, as could happen in the case of cerebral paralysis, retards the acquisition of language, limits the exploration of the environment, and in this way reduces cognitive development. Given that the social net of the child is narrowed, the development of his interpersonal abilities, which are essential for his future life, is blocked.

In addition to the effect of a limitation of the child's psychic and social functions, there also exists the frequent combination of physical disabilities and other kinds of organic illnesses, such as infections of the respiratory system, disturbances of deglutition connected with malnutrition, serious dental alterations, and frequently repeated urinary infections. These health problems reduce the well-being of the child and imply work for the family and the health services. Confronted with this accumulation of different pathologies, it is important that the medical team in charge of the child constantly assesses the different areas which are potentially involved in the deficit. This necessity involves the physically handicapped child being placed under the coordinated action of a wide multi-disciplinary professional group which relies upon modern methods of diagnosis and assessment, such as metabolic examination, computerized axial tomography, and magnetic resonance or SPEC. The high cost of such specialized tests lowers the possibility for children from third world countries to take advantage of and benefit from them.

The role of the pediatrician is crucial in the coordination of treatment of the child with physical limitations. The pediatrician is responsible for early diagnosis, a suitable assessment of a child with a handicap, and the first information about the situation which is supplied to the family. It also falls to the pediatrician to give the first support to the family and to take control of the evolution of the affliction and to create a context of realistic expectations for teamwork which integrates the experts and the family in activity which works to the benefit of the child.

Treatment of a Child with a Physical Deficit

The treatment of children with a physical impediment has undergone very substantial development over

the last thirty years ever since pediatrics became able to reduce the risk of death due to numerous children's diseases. In countries with a lower level of social and economic well-being, medicine experienced a delay caused by a drop in the attention paid to the handicapped child. Overall concern for the disabled child requires a unified and coordinated effort that involves the child, the family, the professional health care workers, social bodies, such as the Church, and public health, educational, and support bodies. The complex needs of this integration often lead to a serious lack of coordination among the different organizations, which double their own functions rather than complement each other's efforts.

Medical Aspects

General pediatric care is essential in the coordination of the activities of the group. The pediatrician can avoid a doubling of effort, assess the real need for treatments or programs of rehabilitation, establish a link with the values of the family, and evaluate the action taken in the medical, diagnostic, and rehabilitation fields. In this way, he can give a human dimension to the child that the specialists often forget.

Pharmacological therapies can have a beneficial effect, as in the case of anti-convulsive drugs or those which reduce such symptomatologies as muscular hypertonia, tremor, extrapyramidal movement, hyperactivity, or aggressiveness. It is very important for the family to understand that drugs have only symptomatic effects so that they do not expect too much from " miraculous " results as regards the deficit. These false expectations lower apprehension about rehabilitative action which is less spectacular but more realistic, given that the inevitable frustration caused by the continuing presence of the deficit aggravates the general situation of the patient and the family. Infant orthopedics can be a valid support in the cure of motor disturbances, reduce deformations, and in so doing facilitate the general integration of the child with physical limitations. There is much discussion about the wisdom of carrying out operations on ligaments and bones, but in general there is agreement on the fact that surgery is the last alternative after all the other possibilities have been tried, such as kinesitherapy, the use of instruments, and occupational therapy.

Rehabilitation in Physical Medicine

Rehabilitation deals with a fundamental aspect of the overall treatment of the handicapped child. The benefit produced for the child is that much greater when the rehabilitation begins immediately after the physical limitation has been diagnosed and when the professional handling of the case is regular and decentralized so as to give the family greater access to the child rather than distancing him. The effectiveness of the physical treatment increases when the parents and the siblings of the child are involved. Their active participation allows him to assess and see his deficit in its proper proportions. The involvement of the patient and the family in the process of rehabilitation creates a good family climate and gives greater continuity to the treatment. It is advisable to make the greatest efforts possible to improve the working of the damaged area rather than concentrating only on the consequences of irreparable damage. The most important challenge for physical therapy lies in achieving compensation for the functions in deficit and increasing the existing potentiality to the greatest degree possible.

Aspects of Mental Health

Overall observation of the child includes constant and careful attention being paid to his cognitive development and to his emotional features. The high risk of psychic disturbance in the handicapped child is connected to his physical and social deficiencies, to long and at times painful treatment, and to the constant frustration of " being different. " With the development of his cognitive abilities, the child needs to understand what is happening to him and why he is different from other children. The little handicapped person has fears and well-founded anxieties which frequently give rise to depressive states which require psychological therapy.

The family has a very important role in diagnosing the deficit of the child. It can happen that the members of a united family do their utmost to protect the handicapped child beyond what is needed and thus limit the emergence of his independence. In other families, the pain becomes transformed into distancing, rejection, and even mal-

treatment. It often happens that parents feel guilty and powerless when faced with the limitation of the child. These are feelings which are added to the sensation of fatigue and disagreement in making therapeutic decisions. These difficulties make themselves felt in the delicate balance within the family and often affect the married couple who withdraw in the presence of a child who needs them. The internal situation can lead to the separation of the couple because of excessive dedication of one or the other of the marriage partners—a situation which, in turn, has a negative influence on the children and especially on the handicapped child. The brothers and sisters can have problems of a behavioral or emotional character because of the special attention given by the parents to the disabled child

The family of the disabled child is at risk. But this can be reduced by the help of integrating preventive or therapeutic measures which are part of the overall system of care and attention.

The family which is willing to support the rehabilitation of the child is weighed down by immense economic problems caused by the cost of very expensive instruments, specialized tests, long treatments, and surgical operations. A solidarity-inspired society should find means of protecting the handicapped child from that other handicap, poverty.

Both the family and the rehabilitation team which works with the handicapped child can encounter new problems. Often there are professionals who are naturally propelled to become involved with the patients and disqualify the family, becoming discouraged when they see that the sick person is not making progress. Other professional workers remain cold and distant and protect themselves from the pain of other people. It is important for the institutions involved in the treatment and care of handicapped children to have enough space for the work of a group to take place, and where this is therapeutic, there should be work satisfaction for its members

Educational Aspects

The upbringing of children with physical impediments involves important challenges. The educational needs of each handicapped child especially require an adaptation of the basic educational program to his characteristics. This is often a need which cannot be met because of a marked lack of differentiated programs, especially in the case of pre-school and adolescent subjects.

There is great controversy about the integration of the disabled child and normal education. Parents and teachers often oppose the inclusion of handicapped children in normal courses. Although the classmates regularly accept them without difficulty, these children, when they engage in comparisons, can develop problems of self-esteem and alterations in the growth of organs not affected by the handicap. Experience of work with handicapped children suggests that it is a good idea to integrate the child into a normal school for a part of his day and give him an education designed to offer him the cognitive means and the ability which will give rise to a future life which will be independent

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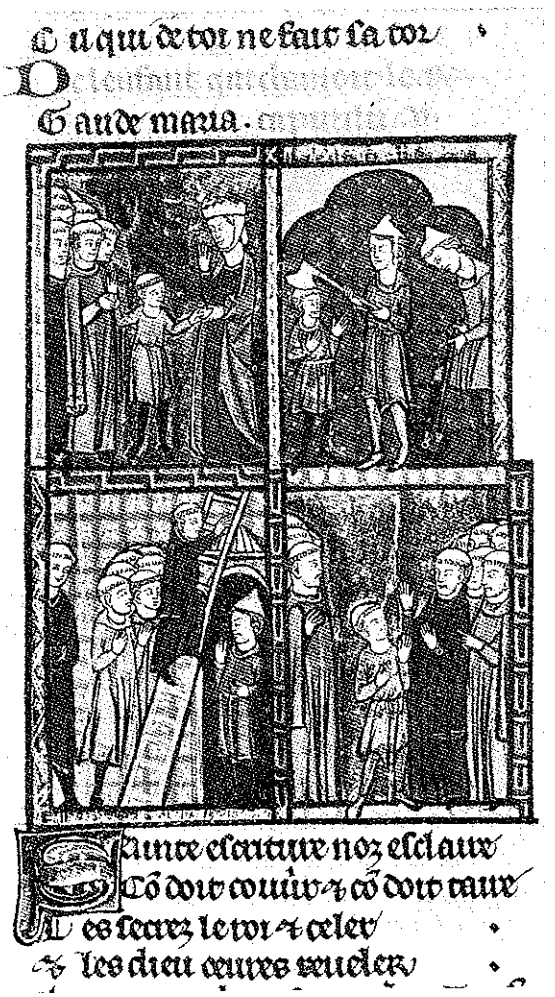


PAUL Cardinal ZOUNGRANA

The Human and Supernatural Value of Suffering Caused by Limitation

Within the context of the topics which have been discussed hitherto over the course of this morning's deliberations, my contribution on " suffering caused by limitation " finds its first subject in the suffering of disabled and handicapped people. Nonetheless, it is in order to achieve a more effective renewal of the human and supernatural values of suffering caused by limitation that I have it thought it suitable to outline the supernatural, human, and general framework within which it is necessary to consider such suffering.

Let us recall immediately that His Holiness Pope John Paul II has already spoken at length in his Apostolic Letter *Salvifici Doloris* on the Christian meaning of suffering. The time I have available does not allow me to dwell in full and complete fashion upon the subject under consideration. I hope, however, that these few reflections that I will offer will be of use to you in your future personal thoughts on the matter.

I. The Limitations of the Creature and the Transcendence of Persons

We instinctively conceive of life as health, as well-being, and consider suffering as something that hinders our human growth, as an accident in life. But reality comes up against this conception of life in violent fashion. We must recognize that suffering is inscribed in our life tissue—that is to say, in the potential of our corporeal being and in the faculties of our critical conscience. These two elements are the energies of our individual and social vitality; they can also throw us into a state of insecurity and suffering.

" At the entrance to my own being, " wrote J.B. Metz, " I already find myself amidst something strange. Not only I myself in my being am introduced into the corporeal, but the world also is alien..... And because the 'medium' within which I am present is also the result and the field of expression of energies which are hostile to me, my corporeal manifestation, which is the visible becoming of myself, has a character marked by ambiguity ".[1]

The author talks about ambiguity because within his body man finds himself in a field of interference between the self and the world—that is to say, between the self and a collection of influences which do not spring from spiritual self-awareness of his own person: the environment which surrounds him, inheritance, certain characteristics resulting from temperament or gender, illnesses, and even the decisions of other people. From this it follows that what he really is can be hidden from that which is foreign to him and that which is foreign to him can seem to be a quality that is part of him. All this can influence human action and often can even compromise it. But, notwithstanding the limitations taken into consideration, the fundamental freedom of decision remains a reality.

" Man, " writes Maritain, " is an individual who leads himself by intelligence and his own will; he exists not only from a spiritual point of view—in him there is a richer and higher existence, a spiritual super-existence in knowledge and love..... In philosophical terms, this means that in human flesh and bones there is a soul that is a spirit whose value is higher than the whole universe. The human person, even if he is a product of small accidents of matter, owes his existence to the existence of the soul which, in turn, overcomes time and death. The roots of his personality are given by his spirit ".[2]

Taking this conception of things as a point of departure, when we state that the sick person or the handicapped person is a " person " and that he has the same rights as other people who are not so afflicted we wish to affirm that he is born, first and foremost, as a " person " and not as a " handicapped person. " We must attribute to him, insofar as this is possible given the limits that his condition places on what he is able to do, the same responsibilities as other people.

II. The Meaning of Limitations and Their Resources from a Natural Point of View

In the search for the meaning of the suffering experienced by handicapped people the journey embarked on by man comes up against two types of limitation:

1. As a finite being, the meaning of everything and the global meaning of existence escape him, and it is only through faith that he is able to come to be aware of what their meaning is.

2. Man reaches these very limits when he encounters suffering. We can find a meaning to pain thanks to the love of someone or some-

thing. But what could this person, or this thing, actually be?

Faith helps us to give an answer: " God calls us to transcend ourselves completely in a love of God and our neighbor which is similar to the love which inspired the life of Christ and, therefore, to transcend ourselves in objective, not subjective, values and in values that are not of this world but which have been revealed to this world through the Bible in general and through the word and the example of Christ in particular. Finally, the self-transcending values are one person —Christ. "[3]

But what answer can our reason give if it is left to itself? In the opinion of the psychologist Viktor Frankl, man should have this ability. The " noetic dimension " which distinguishes man, he argues, leads to a desire to find a meaning to everything, to " always " seek and to find, in any situation whatsoever, a meaning to things. It is this which " makes man man "; it is this which is his distinguishing mark. Indeed, even if man is conditioned by biological, psychic, or environmental factors, he is not " pandetermined. " In his deepest and truest reality he always remains " free. " Not only " free from, " but also, and above all else, " free to " achieve an aim, discover a meaning. This is where the unique and singular " responsibility " of the human person is to be found. Man is the " being who decides himself " in the sense that he constantly directs himself towards a search for the meaning of life, for a being to love, for a cause to serve. Indeed, it is this which is the self-transcendence of man. In achieving this tension man fulfills himself, becomes himself in an authentic way. This is because self-fulfillment is the fruit of self-transcendence.[4]

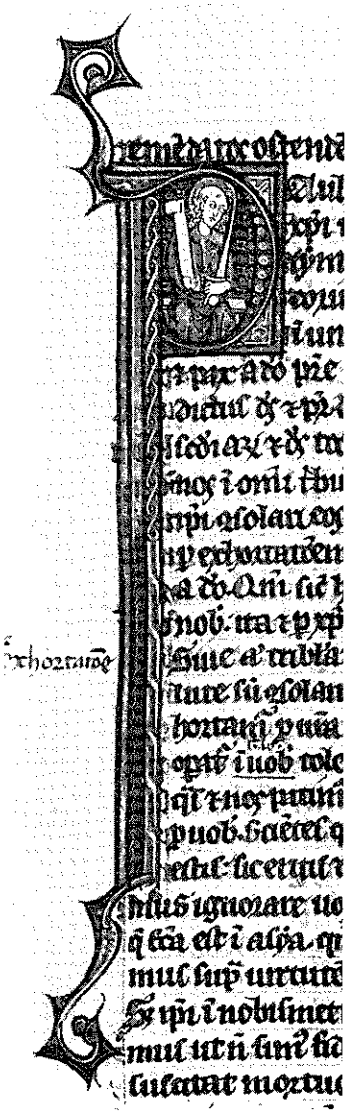
The same author also finds in suffering the place in which man could more easily discover the meaning of his existence. In suffering is to be found the greatest possibility of meaning. Indeed, in this experience, the man freed of conditioning which he experiences in other categories of values uniquely avails himself of himself and this fact and can adopt an attitude to pain which enables him to discover its meaning and the appeal which is made to him.[5]

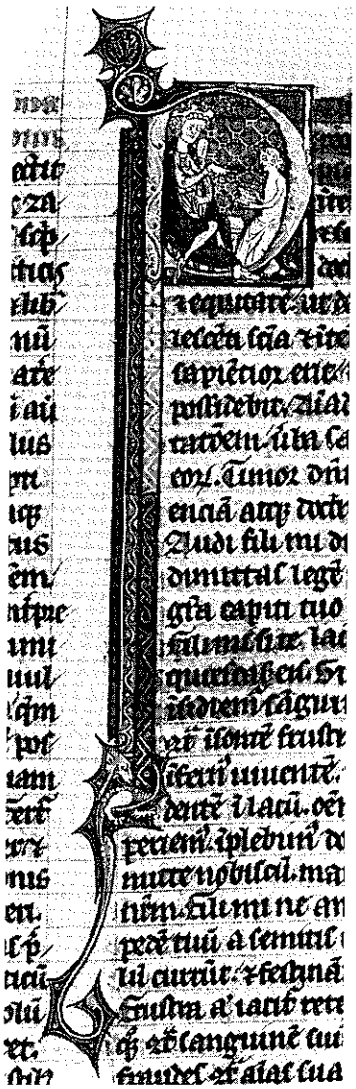
However, no choice starts from a completely premise-free position. In carrying out his activity, the human person must always make reference to what comes to him from outside. In contact with these limit realities, his creative impulse discovers new opportunities for choice which determine the subsequent acts of his existence.

It is precisely this element of impressions from the outside and expressions from the inside, this tension between the ideal to be accomplished and practical reality, that provokes in man the emergence of the spirit from corporeality. The influences which, therefore, work on the activity of self-fulfillment are not only the limits on human freedom, they are also opportunities to express his possibilities, calls for him to overcome himself, to strive towards " what is above. "

The integration of the different existent tensions within the human structure should come about precisely though this striving towards " what is above "—an integration which makes the person capable of employing those faculties and energies of his which are truly available in order to carry out and accomplish his mission.

This ability, conceived as the state of health of the person, is quite often associated, but not necessarily, with a state of psychophysical effectiveness on the part of the person. Indeed, a life capacity can come about of an authentically human character also within a lesser psychophysical effectiveness. There also exist cases where there is an incapacity as regards human life in a state which is fully endowed with psychic and physical potential. In other words, we could encounter people who are wholly healthy, notwithstanding the presence of serious psychophysical impediments, because these latter are well integrated by these subjects. In the same way, there exist people who, because they are badly integrated, are ill, notwithstanding the fact that they possess their full physical and psychic potential.





III. The Christian Meaning of Suffering Caused by Limitations

With regard to this subject it is useful to remember the fine statement of Father Pio of Pietralcina: " The great service which we can render to a suffering person is to give a meaning to his suffering. " Indeed, illness and suffering are always felt by man as being an aggression from the outside which compromises his psychophysical health and hinders him from fulfilling himself. It is natural that questions are posed concerning the meaning of illness, and it is also natural that these questions call for an answer from God.

The Bible devotes serious consideration to this call and answers it in an evolutionary fashion along the lines of the advance of the Judaeo-Christian revolution. In the Old Testament we can already find a dual approach to the problem. The first, which is ancient and very common, sees sin as the cause of physical evil, and thus illness, in all its manifestations, is a consequence of sin. This vision comes to be disputed by the author of the Book of Job, who achieves a major upheaval and opens the way to the second approach. This new conception draws attention to the suffering of good and innocent people, which is considered at length in the Book of Job, by Isaiah in relation to the subject of the " suffering servant, " and, much later, by the Book of Wisdom, whic it dwells upon the good man persecuted by the wicked. Suffering begins to be considered as a special route towards salvation, even if it is of a paradoxical character because it is a redemptive and purifying force which works to the benefit of the patient himself and other people. This conception emerges fully and finds its full expression in the New Testament in the very person of Christ, the Word made Flesh, who freely accepted following the way of suffering in order to redeem mankind, the victim of sin and death.

Indeed, Jesus did not propose a philosophy of evil, a theoretical discourse on suffering. He preferred to be aware of the limits to the condition of man. In this way he was able to change their meaning and their purpose through the Easter itinerary of his passion-death-resurrection.

In this context, the words of Saint Paul used in the formulation of the subject of this seventh international conference, entitled " Your Members Are the Body of Christ, " encourage us to engage in another reflection. And these other words of Saint Paul himself help us to introduce us to this reflection: " I live; or rather, not I; it is Christ that lives in me " (*Ga* 2:20). In other words, for the reborn man there is a new and characteristic existence—he is no longer a man in an individual sense, a self that is in himself living or suffering, but Christ who lives and suffers in him. Christ has made him an instrument of his redemption.

Indeed, when Christ dies and rises again he does not bear a " flesh " which is foreign to him. Because of the hypostatic union human nature finds its place in him in its wholeness. For this reason, it is all mankind which is crucified with him, which dies with him, and is resurrected with him. In his suffering and his death, every death and every suffering are present. On this subject Pope John Paul II declares in his Apostolic Letter *Salvifici Doloris* that " The Redeemer suffered in man's place and for man. Each man takes part in one way or another in the Redemption. Each man is called to participate in the suffering through which the Redemption was achieved. He is called upon to take part in the suffering by which every human suffering is redeemed. In achieving the Redemption through suffering Christ, at the same time, raised human suffering to the level of giving it the value of redemption. Each man, therefore, can participate through his suffering in the redemptive suffering of Christ " (*SD*, 19).

In this sense we must speak of a " belonging " of man to Christ. This is because he is a fruit of the vicarious substitution of Christ, " who gave his life for us " (*1 Jn* 3:16). We must also speak of an " assumption " of man, of his existence, of his suffering, and his death. Man, whether he knows it or not, passes through the vicarious action of Christ; he has been as-

sumed and transferred into another dimension. He has been embodied in Christ. The " mystical body " is present precisely on this basis.

With regard to limitations of the person as causes of suffering, the moment has come to affirm a truth recognized by everybody—death is the greatest limitation, the most common disability, something known by every man. It is the supreme proof of that fact that he must end. It places a barrier which cannot be avoided in front of his deepest wish for eternal life. Now, Christ, the Word made Flesh, plausibly assumed this limitation when he died upon the cross. He then broke it through his victorious and glorious resurrection.

In this way, through death itself, infinite life is now accessible to all men through Christ in the form of eternal life. The natural wish for infinite life is also transformed into " hope, " that theological virtue that Saint Paul declares does not disappxoint (cf. *Rm* 5:5).

From this moment, having defeated the supreme and extreme limitation, psychic and physical handicaps are no longer to be endured by man. They can and must be accepted with optimism and, in certain cases, be experienced as a special grace for oneself and for others. " This, " declares Pope John Paul II, " is the truly supernatural and at the same time human meaning of suffering. It is supernatural because it sinks its roots in the divine mystery of the redemption of the world, and, on the other hand, it is profoundly human because in it man recognizes himself in his humanity, his dignity, and his own mission " (*SD*, 31).

Indeed, man, in belonging to Christ, when he is disabled as well, takes part in the grace of his mission. Incorporated in to Christ, he is pushed and modeled, to become even more like him (cf. *Ph* 3:10-12). Furthermore, he can be truly associated with the action of Christ—his evangelization, his forgiveness, his activity on behalf of the infirm, his help to all those who suffer . . He can also be associated with his suffering and his death in order to take part in future glory.

I will finish my paper with an observation of a pastoral character. The Christian is someone who feels the duty to make himself the " neighbor " of other people, and in a particular way of those who suffer. For him, helping those who suffer is not only a humanitarian act—it is above all else what is required of faith in the Gospel and a duty of Christian integrity (cf. *SD*, 30). Indeed, it is loyalty to God which helped the saints to be faithful to man to the point of risking their own lives in a physical sense and in the face of incomprehension and slander (cf. *1 Co* 4:10-13).

Nevertheless, whatever may be the handicap of the person who suffers, we must not replace him but render him responsible. We must help him to rediscover within himself the force necessary to react, even though we support him with our presence. Sick and handicapped people do not want to be considered as objects to be cared for but as people who are responsible and are able to cooperate, within the limits posed by their state, in the construction of the community they belong to, whether that community is civil or ecclesial. The relationship of help and pastoral action in favor of the disabled should therefore take place along these lines.

The Pontifical Council for Pastoral Assistance to Health Care Workers, in organizing this seventh international conference, has given Pope John Paul II the joy of seeing thought being expressed in action, the putting into practice of what he said eight years ago: " The discovery of the salvific sense of suffering in union with Christ transforms this depressing feeling (of the uselessness of suffering). Faith in taking part in the sufferings of Christ brings with it the interior certainty that the man who suffers 'completes that which was lacking in the trials of Christ' and within the spiritual context of the act of Redemption it is useful, like Christ, in the salvation of his brothers and sisters. Not only is he useful to others but, in addition, he performs an irreplaceable service. In the Body of Christ, which has grown constantly ever since the Cross of the Redeemer, suffering, which is impregnated with the spirit of Christ's sacrifice, is in precise and irreplaceable fashion the mediation of the source of indispensable benefit to the salvation of the world " (*SD*, 27).

PAUL Cardinal ZOUNGRANA
Archbishop of Ouagadougou, Burkina Faso

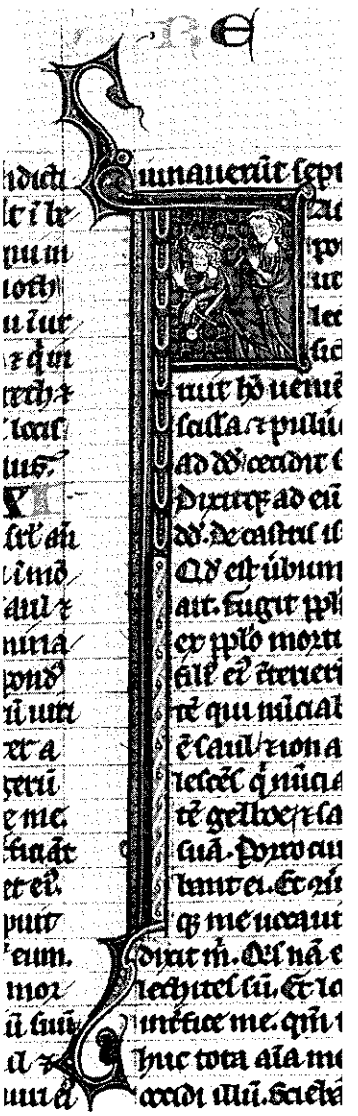
[1] METZ J.B. *Arzt una Christ*, Salzburg, II 1958, p 79, cf. idem *Caro cardo salutis*, Queriniana 1968

[2] MARITAIN J. *I diritti dell'uomo e la legge naturale*, Milan 1977, pp. 4-5.

[3] RULLA L.M. *Antropologia della vocazione cristiana*, Casale Monferrato, Piemme 1985, p. 170

[4] CINÀ G.: cf. *La ricerca di senso della sofferenza negl scritti* di Viktor E. Frankl. Poliglotta de la P.U.G., Roma 1992, p. 328

[5] *Idem*, p. 836.



PAUL Cardinal POUPARD

What Is a Life Worth Living?

Your Eminence, the subject you invited me to talk about is expressed in the form of a question. An answer, therefore, is expected of me. The most incisive minds in the history of mankind have devoted themselves to this immense and difficult task: Sophocles and Hesiod, Plato and Marcus Aurelius, St. Augustine and Plotinus, Pascal and Kierkegaard, Dostoyevsky and Camus. It is a question that man has asked himself ever since he began his painful journey on this earth. This is because it is closely bound up with the question of the meaning of suffering. Indeed, when faced with evil and pain, man is inevitably confronted with the question: what is a life worth living?

In our times suffering is often aggravated by the fact that the man who falls prey to suffering must face up to this evil in a world which is without those values that have the ability to direct his life and give him a sense of meaning. The evil and suffering appear to him as being totally negative and useless, as being things that have no purpose and are of no help to anybody. This is why it is so important to give them a meaning. The discovery and acceptance of the fact that suffering has a meaning involves taking the first step towards liberation and cure, not from suffering but in suffering itself. This is the first step in the direction of St. Augustine's *transcende te ipsum*. As John Paul II wrote in his Apostolic Letter *Salvifici Doloris*: " Suffering seems to belong to the transcendence of man—it is one of those points at which man in a certain sense is " destined " to rise above himself, and is called to do so in a mysterious way " (no. 2).

Indeed, to find a meaning to suffering means that man perceives a further dimension to his existence beyond the opaque realities of his pain-devastated nights and days. This means that he has discovered in his wish to live a depth which projects him beyond the temporal and an aspiration to something more than material goods, which suffering cast doubt upon and relativizes, revealing their ephemeral character. To find a meaning to suffering means to recognize that hope always goes beyond immediate wishes: it transcends everything earthly, wich for this reason can easily be denied us.

Our present-day crisis is also a crisis of truth concerning the meaning of suffering. In a world deprived of meaning, we cannot give a meaning to suffering. For this reason we reject it on the grounds that it is negative and useless. And what would be the case if it were one of the fundamental problems which had to be solved in order to discover the human dimension of our civilization in upheaval?

Suffering and the Meaning of Life Among the Greeks

" Many bad things befall men. The earth is full of evils, and so is the sea. Diseases besiege us day and night. In silent fashion they assault us; they are the bearers of misfortune. " So writes Hesiod in *Work and Days*—quoted by A.J. Festugiere, *The Greek's Religious Ideal and the Gospel* Paris, Gabalda, 1932, p. 162).

Surprised one day in a forest by King Midas, Silenus entrusted to him the spirit of Greek Wisdom: " It is better for man never to be born. If he is born, it is better to return as soon as possible to the Kingdom of Night " (*op. cit.*, p. 163).

Fate, suffering, and death—the pain of living and loneliness of man in the world. This was the deepest experience of the life of that people of most admirable culture we know as the Greeks. Then, as in times of war when the great shadow of death obscures life, they sought happiness in frenetic and eager fashion. Joy down here is certainly short-lived, but it is the only joy that exists. Nothing else, certainly, is promised. In the Greek world, it was from this that there sprang that nostalgia for a free and full existence in the strength of the body and the frenzy of passionate action.

But what action? Is it the activity of the perfect citizen, radiant in his home, happy in his city, healthy in body, and with a soul in harmony? But how rare are such destinies! And as far as regards contemplation, how many have access to such a life? To escape fate, the stoic desperately denies the existence of evil. But he cannot deceive himself for long. There is no way of escaping fate. The gods cannot help him and do not want to help him. Man is a slave, and then dies. It is better, therefore, to give oneself to death. If, on the one hand, Socrates rejects suicide in the *Phaedon*, on the other, the Stoics encourage this liberation.

Nonetheless, some ray of light will introduce clarity of perception into this prison. It is above all the use of the conscience that pain

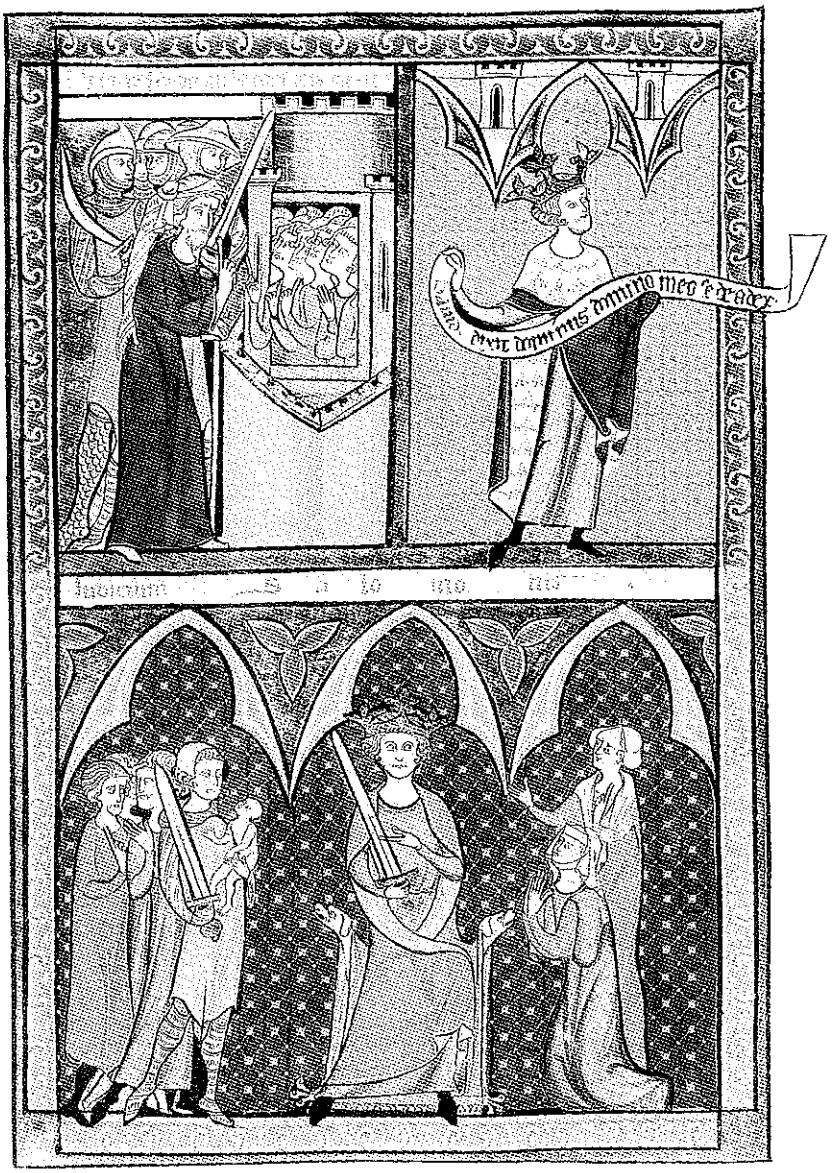
teaches and pain mobilizes. *Suffer and you will learn* was the maxim of Greek wisdom. Alfred de Musset gives an echo of this in those oft-repeated verses: " Man is an apprentice, pain is his master, and he knows nothing until he has suffered. "

There is also the appearance of the idea that suffering and death should be accepted as a sacrifice for an ideal above the physical life and should be beyond any terrestrial consideration. Antigone and Iphigenia choose it, being animated by a sacred fire. It is the wish for the celestial, longing for those happy regions inhabited by the gods—there is an escape to another life!

Plato understood this impulse towards the on-high, this need for evasion towards the divine world, this desire of the soul to unite with the divine through contemplation. But is the soul loved by the God it contemplates? The soul thinks constantly about God, but does God think about the soul? Does he worry about the world? Is this love that goes up matched by a love that comes down? As realities stand, there is no sign of love within him, and for good reason. The God of the Greeks is not a living Being. He is, rather, a fine model produced by a vision of ourselves, or, to put it another way, in a latent perspective of pantheism, the soul of the world. From this moment, the union with God to which man aspires can never be the gift of ourselves to Another who loves us and who, in turn, gives himself to us. There is no personal exchange of two loves, but at the most the loss of our consciousness in the divine unconsciousness.

The Idea of the Beautiful, the Soul of the World, is very small when compared with the ocean of human suffering. A God without love is not able to justify so many tears. What is the cosmic order worth if the condition of man implies such a natural disorder?

This is the final point of Greek wisdom. It has given no reply either to the question as to the meaning of life or to the question of the meaning of human suffering. The Cross alone throws light on the obscure impulse of the human spirit. The idea that happiness cannot be obtained without the total



giving to a being who is higher than us and that pain enables us to grow—an idea that is the secret force of tragic heroes—thus found its true fulfillment. The most lonely of hearts accepts its suffering if it can offer it to God, for He Himself suffered for that heart.

Suffering and the Cross

The first ray of light that illuminates the meaning of suffering, and thus the meaning of existence, for the Christian, comes from the Cross of the Savior. " For Christ and in Christ that enigma of pain and death, which outside the confines of his Gospel oppresses us, is illuminated. " Such is the affirmation of Vatican II (*Gaudium et Spes*, no. 22).

Charles du Bos, when he was afflicted by a serious malady which a few months later would lead to his death, wrote in 1937 that the body is " according to the unexplorable plans of God, at times the radiant memory of the glories of the Creation and at times the enigmatic instrument of torture entrusted with the task of carrying on the work of the Cross down here on Earth. " (" On Physical Suffering, " in *Approximations*, Paris, Fayard, 1965, p. 1480).

Illness, du Bos went on, " is the reign of the static, of the immobile. Much more than a crisis or even a series of crises, illness is a state that lasts, which lasts indefinitely and

which remains immobile. It is in this respect that the analogy which is frequently made between illness and the cross is the truest—indeed, the only true one. The sick person is on the cross. He is nailed to it, he will never be able to get down from it by himself. In front of the sick person there is Time. A time which is not only endured in all its heaviness and weight but which, in the eyes of the sick person, is as immobile as his cross. There is no other way to make it disappear: the time that passes has become for him time that does not pass at all. Within the temporal framework of the sick person, there is neither past nor future: it is a framework made up of only the present moment, of identical moments which never stop succeeding one another."

At the end of these reflections, Charles du Bos addressed the following words to Christ: "Lord, thank you for having said to me, 'My soul is sad until death.' If you had not said that, would we dare to turn our heads towards the crucifixion during these unending hours when our being is summed up by that verse of Baudelaire: 'Sadness wells up in me like the sea?'" (*ibid.*, pp. 1481-1485).

The Christian Meaning of Suffering

In looking at the cross of the Lord, man slowly comes to discover the hidden meaning of suffering. "The person who suffers," declares John Paul II, "cannot but notice that the person to whom he addresses his question is himself suffering and wants to answer him from the cross, from the center of his own suffering" (*Salvifici Doloris*, no. 26). This is because God sympathizes with someone who has suffered and who takes a step backwards when faced with the cross. He will not be the one to tell us that it is easy. "Christ, indeed, does not answer directly and does not give an abstract answer to this human question about the meaning of suffering. Man hears his salvific answer as he comes to be a participant in the sufferings of Christ" (*Salvifici Doloris, no. 26*).

Introduced into the mystery (ery of the Cross, man "finds there almost a new means of assessing his own life and his own vocation. This discovery is a special proof of the spiritual greatness which, in man, rises above the body in an incomparable fashion. When this body is profoundly ill, completely disabled, and man is almost incapable of life or action, at that time interior maturity and spiritual greatness express themselves even more and constitute a moving lesson for healthy and normal men" (*ibid.*).

In addition to the interior maturity and spiritual greatness which it creates, suffering effects purification within man, and this prepares him for the intimate life shared with God. In this sense, it has a prevalently eschatological function.

If it was merely a question of contemplating God eternally as a beautiful spectacle, such total purification would undoubtedly not be necessary. But our vocation consists in always living in conjunction with his life, in becoming able to love as He loves. No trace of selfishness can exist where there is only love. For this reason the highest vocation is accompanied by the highest need—to be complete love without any withdrawal into oneself. Or, rather, there is something in us which is different from love: we are always to a certain extent owners of others and above all else of ourselves. To be of God, we must not be of ourselves. To not be of ourselves, we must be distanced from ourselves. This uprooting is what suffering is, for suffering is like a partial death. And earthly death terrain is nothing but the end of this movement of giving up oneself until there is nothing left to us of ourselves and we thus belong totally to God—we are in pure relationship with Another and other people, the true definition of love. We must be deprived totally of everything in order to enter into eternal love. God has nothing because He is everything and because this everything is total giving.

But suffering does not have only an individual meaning, in the sense of interior growth and a giving up of oneself which prepares the Christian for the eschatological meeting with God. It also has an ecclesial meaning which was highlighted by Saint Paul. In his letter to the Colossians the apostle writes: "I am glad about my sufferings on your behalf, as, in this mortal frame of mine, I help to pay off the debt which the afflictions of Christ leave still to be paid, for the sake of his body, the Church" (1:24). And he addresses this question to the Corinthians: "Have you never been told that your bodies belong to the body of Christ?" (*1 Co* 6:15).

In commenting on these passages John Paul II writes in *Salvifici Doloris*: "This Redemption, even if carried out in all fullness with the suffering of Christ, lives and develops in its own way in the history of man. It lives and develops as the body of Christ—which is the Church—and in this dimension every human suffering, because of union in love with Christ, completes the suffering of Christ" (no. 24).

If we understand fully the meaning of the Cross, we will not run the risk any more of thinking of suffering as something which is negative and useless in our lives. Not only does it help us to grow in a spiritual sense but, at one with the passion of Christ, it makes the Church grow. Here is its good side and its value, things which have so often been emphasized and stressed by the saints.

Suffering is to be understood with reference to and within the context of the mystery of the Redemption. Its final stage is the Resurrection and the glorification of our body, and here the eternal will of God is magnificently asserted: that everything within us should be life and freedom, nobility and beauty, greatness and joy.

A life worthy of being lived is a life of love in which suffering finds its meaning in the cross carried in exemplary fashion by the saints in imitation of Jesuus Christ.

PAUL Cardinal POUPARD
President of the Pontifical Council for Culture

SIR JOHN WILSON

Global Action for the Prevention of Disability

In the village church which I attended as a child, there were pictures of Jesus restoring sight to blind Bartimeus and hearing to a deaf man, telling a paraplegic to get up and walk and stilling the anxieties of a mentally-disturbed outcast.

When I myself lost my sight, through a school accident at age twelve, I was puzzled by the memory of those miracles. Now, after fifty years in international action for rehabilitation and the prevention of disability, I have come to see the message of those miracles as, in a sense, a prophecy and promise of the advance of healing science and the technology of disease control.

The past twenty-five years have witnessed the beginning of revolutionary change in the world's capability to prevent causes of disability which affect massive populations. The United Nations General Assembly last month recognized that these changes place disability issues, as never before, at the center of world health and development policy.

Two months ago, in East Africa, the United Nations Task Force on Disability accepted as a reasonable objective an attempt over the next ten years to reduce by at least one third the incidence of some of the major causes of avoidable disability in developing countries. That may seem a startling claim, so let me briefly outline six areas of action which could, we believe, make that possible.

A fifth of the world's population lives in communities at risk of disability through lack, in their diet, of the micronutrients: iodine, vitamin A, or iron. Earlier this year I was in the Philippines, where, in the mountainous regions, one child in eight is born mentally retarded through lack of iodine, which is leached out of the soil and out of the food chain by many years if deforestation. Replacement of those micronutrients is one of the most cost-effective interventions in environmental health and, on a global scale, could protect at least 900,000 children annually from disability.

During the past twelve years, in what has truly been called a " child survival revolution, " immunization of children against six disabling diseases has increased from a coverage of less than 20% to almost 80%. That is already reducing childhood disability by at least one fifth. As the program reaches its targets, including the eradication of poliomyelitis, at least another 250,000 each year should avoid disability.

Every half minute, somewhere in Africa and Asia, a woman dies or is disabled by mismanagement of the hazards of birth and pregnancy. More than half of the births in developing countries are handled by untrained birth attendants or family members. One result is that, each year over a million babies are born brain-damaged through birth asphyxia and other causes. The international organizations have set the target, over the next ten years, of halving that appalling toll of disability and death at the very fountain of life.

The International Labor Office estimates that, each year over a million workers are disabled by preventable, occupational injuries. In some communities road accidents now exceed disease as a cause of disability. These injuries do not just happen—they are caused by negligence, inadequate engineering and maintenance, drunken drivers, and industrial pollution. We need mechanization, but those consequences need not be tolerated in a civilized world.

The primary health systems which are now in place in most developing countries are the most powerful mechanism for change. At that level we can act against a whole range of disabling diseases: trachoma, otitis media (which causes 40% of hearing impairment), and leprosy, through multidrug therapy. In environmental health, significant events are taking place: river blindness, which previously darkened the lives of whole communities in West Africa, is coming under control, as is Guinea worm disease, which formerly incapacitated two million Africans each year.

One of the most striking advances of recent years has been the simplification of surgical procedures to the point where they can be safely undertaken in rural areas. Last year, in India alone, 1.2 million blind people had sight restored, mostly in village eye camps. Middle ear operations have been demonstrated which might offer a chance of improved hearing to twenty million people. International orthopaedic organizations say that, with timely basic surgery, at least a third of the people with lower limb impairment in developing countries might have effective mobility restored. It is an extraordinary fact that half of the blindness in the world is due to curable cataract.

Together with rehabilitation and equalization of opportunity, pre-

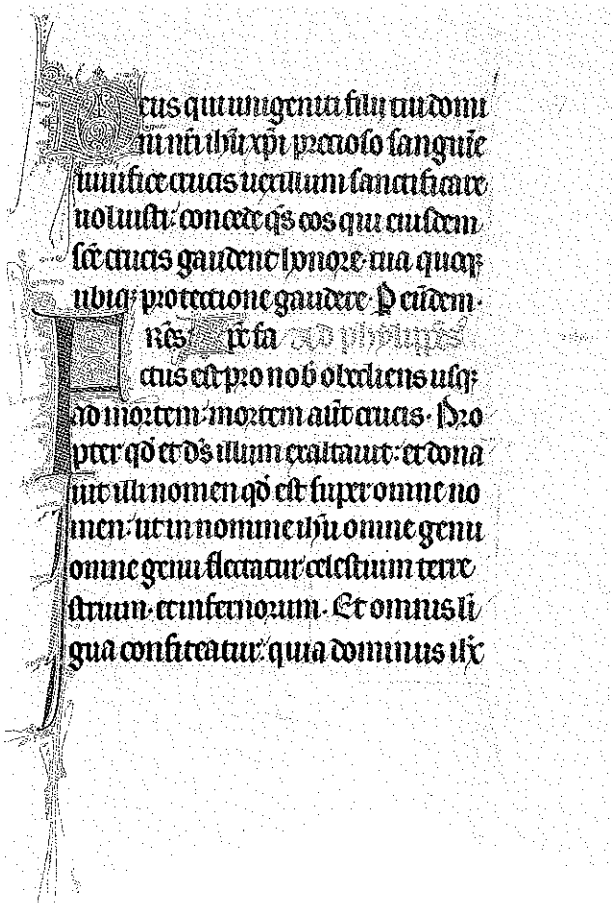
vention is one of the three basic aims of the World Program of Action. It was to advance this cause that, ten years ago, three United Nations Agencies formed the International Initiative Against Avoidable Disability, which is now known as the impact Program. We are convinced that points have now been reached from which preventable disability, with all its consequences in frustration and economic loss, need no longer be an inescapable part of our human predicament.

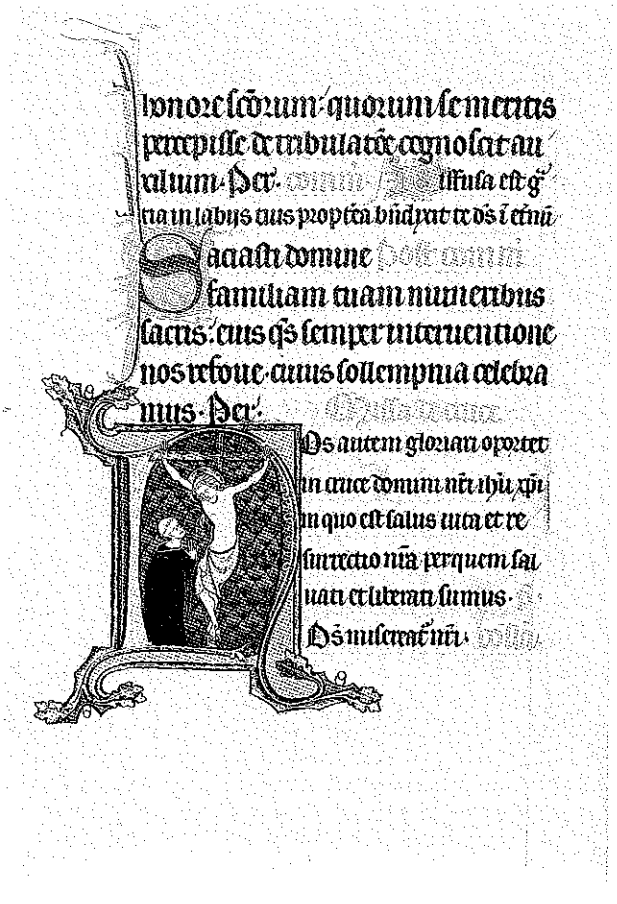
That will happen only if the great mechanisms for change in the world are geared to this process of prevention. One of those great mechanisms is here in the Vatican and in the network of churches throughout the world.

Last time I was here in Rome I found, in a church, those same miracle pictures remembered from my childhood. Might it now be appropriate that, alongside the picture of the restoration of sight to Bartimeus, there might be set the picture of an eye surgeon at work in a village eye camp? Alongside those pictures of the deaf man and the paraplegic, might we set a picture of the mobile ear unit in Thailand or an orthopaedic camp in Central Africa? Beside the picture of the miracle of cured leprosy, might we now set a picture of Asian missionaries distributing multi-drug therapy or, perhaps, Impact's hospital train taking curative surgery to the remotest villages of India?

At the heart of most religion is the concept that the Kingdom of God is within us. I am neither a theologian nor a philosopher, but I wonder whether one implication of that concept might be that the powers of the Kingdom are potentially within mankind. Less pretentiously, may we say that, for those things for which, in any language, we have the temerity to pray, we may occasionally be given an opportunity to act.

Sir JOHN WILSON
Senior Consultant, United Nations Development Program (IMPACT)





YERKER ANDERSSON

Deaf People and Their Integration into a Hearing and Speaking World

Equalization of opportunities and participation in society have become important goals for organizations of persons with disabilities around the world. Thanks to the *United Nations World Program of Action Concerning Disabled Persons*, more and more countries around the world have at last acknowledged that the removal of barriers in both architectural environments and communication is necessary for these individuals' participation in society. Nations have, for example, agreed to install ramps in cities for those with mobility limitations, to provide publications and directions in braille for those whose vision is limited, and to offer sign language interpreting services, telephone relay services, and television captioning for those with hearing loss. These responses have indeed increased the participation of persons with disabilities in society. For example, without my sign language interpreters, I would not have been able to deliver my lecture here or to interact freely with members of this distinguished audience. I am grateful to the Vatican for its decision to remove the communication barriers by providing sign language interpreting services for me.

I am a professor of sociology at Gallaudet University, the world's oldest—and only—accredited university devoted exclusively to the education of deaf and hard of hearing persons. My professional field, sociology, has concluded that integration occurs only when—regardless of the differences among individuals' physical, sensory, and mental capacities,—human beings face no barrier in any social, economic, or political activity within society. The societal acceptance of variations, both between and within human groups, is a crucial factor for participation in economic, social, and political activities. Since 1949 I have travelled throughout Europe, Africa, the Americas, and Asia and met deaf persons, is those who use sign language in their group interaction, and have regularly visited their clubs. I also spent my sabbatical leave studying local and national organizations of the deaf. through on these experiences, I have again and again come to the conclusion that the participation of deaf persons in society tends to be greater in those countries flexible enough to accommodate the needs of different human categories rather than those insisting on a single category. As human nature is incredibly rich in its variations, it is impossible for most human beings to reach physical, sensory, or mental perfection. Contrary to medical assumptions, human beings have always been able to find different ways to compensate for their physical, sensorial, and mental limitations.

Here I will specify and discuss some of the integration efforts used by deaf people and those in the hearing and speaking world where deaf people live.

Schools, churches, social welfare agencies, and other programs designed to work exclusively with deaf individuals still exist in most countries. Organizations of the deaf have for a long time supported this philosophy. Deaf people acknowledge that this kind of integration can be good for persons with disabilities, provided that they and the society in which they live share the same method of communication, that is, listening and speaking. But from their own experiences, deaf people feel that it is necessary for persons with hearing loss to acquire sign language in a special environment that only schools, churches, and other programs for the deaf can offer. This bilingual approach is now being adopted as the ideal one in many countries. As studies in psychology, linguistics, and sociology have repeatedly concluded, sign language is very important for the intellectual, social, and emotional development of deaf individuals; there is a growing consensus in many countries that schools, churches, and other programs for the deaf should be preserved. UNESCO, in 1984, acknowledged the importance of such programs for both the acquisition of sign language and the preservation of the deaf group as a cultural enrichment.

In the past many countries have tried to teach only speech and lipreading to deaf children, hoping that they would eventually become integrated. This philosophy has not worked well because it has failed to recognize their natural language, namely sign language, and deaf people as a sociocultural variation. Some countries have attempted to close schools for the deaf or other programs by sending deaf persons to regular programs, either with or without support, such as interpreting services. Organizations of deaf people have resisted such an effort because their leaders feel that regular programs, even with interpreting services, cannot give the same intellectual and social opportunities as deaf persons receive during group interaction at schools for the deaf, churches, and other pro-

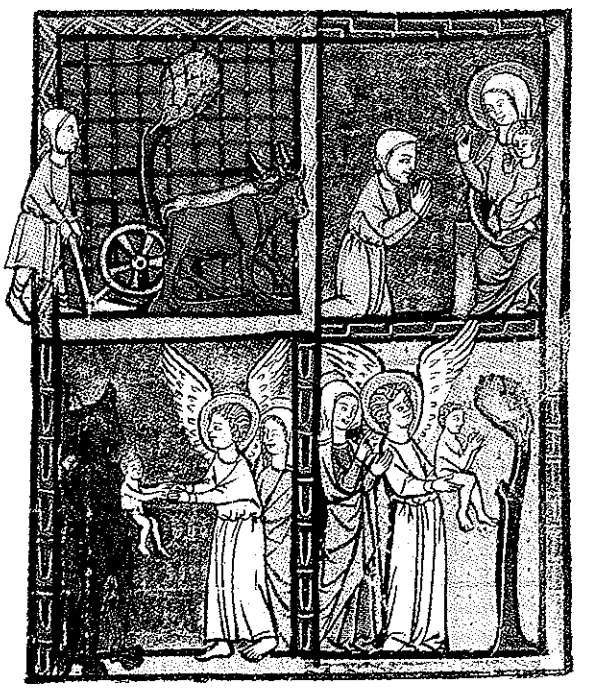
grams. Very few industrialized countries offer a choice of a program for the deaf, a program for the deaf at any regular school or a regular program. Such an option can occur only in wealthy countries.

This brief description does not necessarily imply that deaf people have refused to become integrated with other individuals in the hearing and speaking world. Contrary to the assumptions of scientists, educators, and political leaders, deaf adults have, in fact, been more or less integrated with hearing people in different ways. *Firstly*, the majority of deaf people in most industrialized and a few developing countries have for more than one hundred years been employed at factories, offices, laboratories, shops, and other places of work. They have been able to interact with their colleagues with normal hearing by using speech and lipreading, by writing pad and pencil, or by using interpreting services. Without such willingness to recognize variations in communication, no interaction can occur between deaf and other persons. *Secondly*, deaf persons do participate in society by watching captioned television programs, reading newspapers, and attending interpreted lectures, meetings, church services, and museum tours. Television captioning and sign language interpreting services have brought dramatic changes into the lives of deaf individuals. They no longer feel limited or dependent, compared to persons with normal hearing, in the awareness of current local, national, and world affairs. With interpreting services, they can now share their own feelings or thoughts at meetings with persons outside their group. *Thirdly*, over 35 countries have established a text telephone network among deaf persons, stores, airports, government agencies, etc. and a relay system permitting deaf persons to communicate via telephone with those with normal hearing. These unprecedented innovations have considerably increased the participation of deaf persons in society. *Fourthly*, deaf people have been willing to teach sign language to persons with normal hearing. Courses in sign language now are offered by local organizations of the deaf, high schools, and universities. Those parents of deaf children taking a course in sign language have reported that it has made their relations with deaf children closer and more meaningful.

During my visits to countries in Europe, Africa, Asia, the Americas, and other parts of the world since 1949, I have not been able to find a country where the entire deaf population is completely cut off or lives in full isolation from society. Deaf people in practically every country do want to interact with persons with normal hearing in different ways. However, deaf persons find that their concerns are peculiar to themselves; they prefer a place where communication is clear and comfortable, such as a club for the deaf. In major cities throughout the world deaf people congregate in their club at least once a week to share their joys and disappointments. This kind of social life is not different from those of occupational groups, ethnic and linguistic minorities, and other human groups.

Along with the activities of persons with normal hearing found in each of at least a hundred countries, deaf people have established associations and have organized their own events, championships, and other activities on a regular basis at every level, from local to national and international. In this way deaf people have used society as a source of inspiration for their activities, which in turn become a cultural enrichment for society. This conclusion again is true of ethnic groups, linguistic groups, and other cultural variations. At the international level, deaf people have already established three organizations which have been recognized by the United Nations, the International Olympic Committee, and the World Chess Federation.

We conclude that in general the degree of integration depends on both the willingness of human groups to function within a society and the societal tolerance of human variations. Activities created by ethnic, religious, and linguistic variations and persons with disabilities are the reflections of those maintained by the society where they exist. In this sense, they are becoming integrated into the society. The societal accommodation of the needs of different human categories is an acknowledgment of variations within society. And the societal willingness to recognize individual variations within each human cate-



gory is an acknowledgment of differences among human capacities. Once this acknowledgment of differences is accepted, society as a whole, or in its component parts, can begin to work on the barriers to integration. These barriers can be attitudinal, political, physical, financial, etc. It is when these barriers begin to fall that society is able to become integrated with its different human groups and reap the harvest of the richness of ethnic, religious, cultural, and linguistic diversity.

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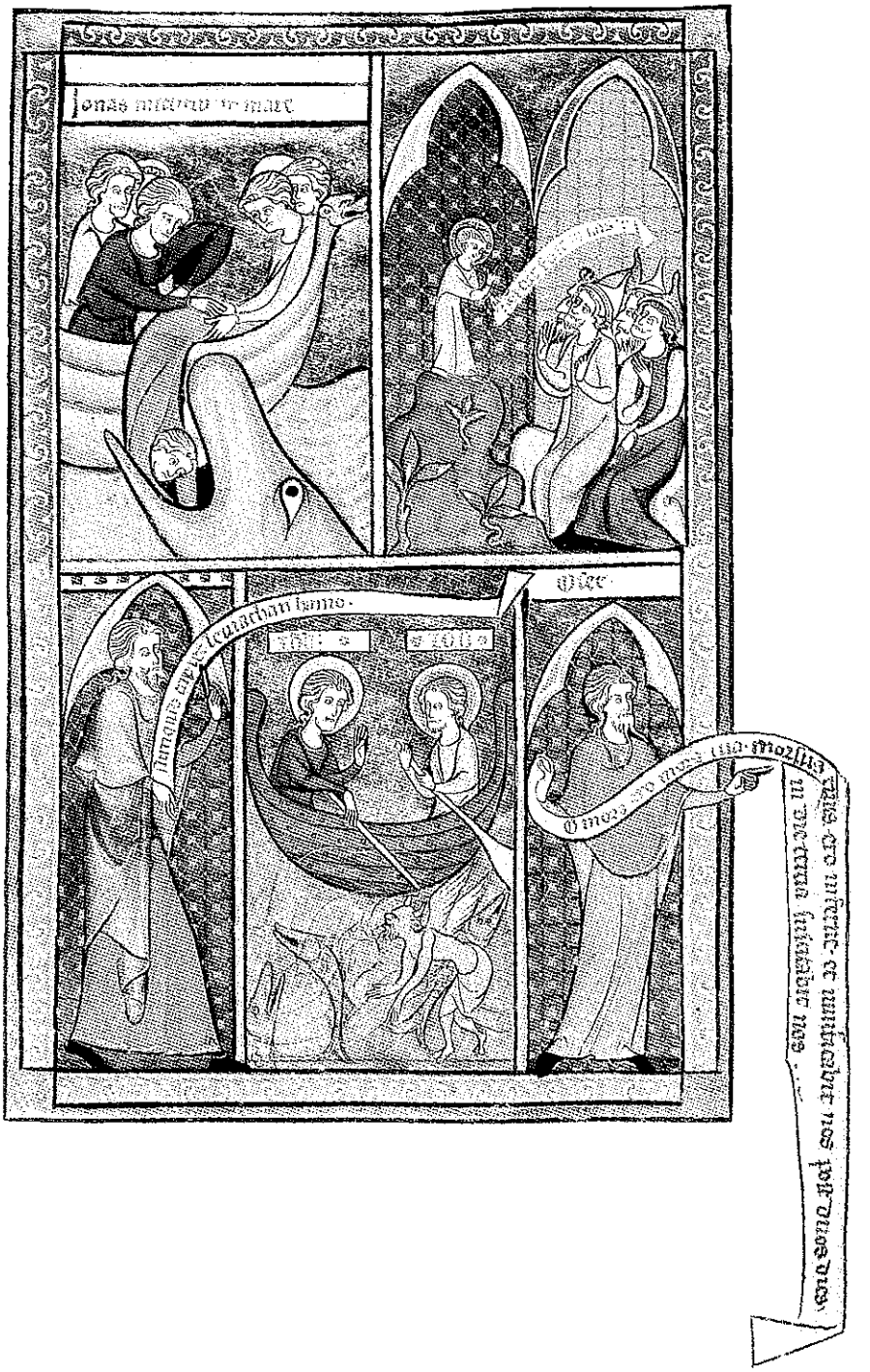


BRIAN P. O'DONNELL

Enriching Lives–Interaction Between Society and Its Members Who Are Disabled

Preamble: The Essence of the Relationship

In May 1988, during a pastoral visit to England, Pope John Paul II referred to disabled persons in society, the subject of this conference, with words that went unerringly to the center of the relationship between society and its disabled members and which defined the essence of that relationship.

The Holy Father said: " *Do not turn away from the handicapped ... Do not push them to the margins of society. For if you do, you will fail to understand that ... weakness is a creative part of human living and that suffering can be embraced with no loss of dignity ... Let us keep the sick and the handicapped at the center of our lives. Let us treasure them and recognize with gratitude the debt we owe them. We begin by imagining that we are giving to them; we end by realizing that they have enriched us.* "[1]

Disabled People Enrich Society

In this talk I intend to draw on my experience as an individual, and as Prior General of a Religious Order that serves many thousands of disabled persons, to delineate how disabled people enrich society, not in spite of their disability, but because of it and through it.

I, together with my religious confreres and our lay co-workers, share the sentiments of the Holy Father; for we know that in relation to the disabled men, women, and children that we meet in our lives and works, we, too, " began by imagining that we were giving to them; we ended by realizing that they have enriched us. " The same idea finds recognition in the Constitutions of our Order, where one reads that we feel " *in communion with those who suffer, in awareness that ... when we serve [them] we too always benefit.* "[2]

Even a cursory look at human history reveals a multitude of people with disabilities who have enriched the human race by their lives, their discoveries, and their artistry.

It is not my intention today, however, to talk about the famous.

I want to speak about how society is enriched by millions of disabled persons whose names will never be inscribed in the history books because they enrich our society within the limited circle of family, friends, and associates, and it is within that sphere that they are recognized.

Personal Note

I would like to say at this point that I am not speaking on this subject simply from an academic point of view. My own sister, who is now 57 years of age, has had a learning disability from birth and now lives in a L'Arche community in Sydney, Australia. I believe that the presence of my sister with her disability in our family had a very positive effect on the way in which my parents brought up all their children. I also believe that the unconditional and unreserved love that I received from my sister in our shared childhood helped to make me the person I am today.

I have no doubt that the experience of having a sister with a learning disability was an essential element in my preparation by the Lord for a vocation to the religious life, and to the Hospitaller Order of St. John, in particular. As a Religious, my professional training and a major part of my apostolic life have been in the area of special education of children with learning disabilities.

Acceptance and Recognition

Having introduced such a personal note, I do not intend to take an emotional line in what I will say today. Statements of parents, siblings, and others about the disabled persons in their lives often unabashedly reflect the depth of feeling that pervades their interpersonal relationships. As such, they can tug at our heart-strings. An example comes readily to my mind in some words of the late John Harriot[3] that I read several years ago in an article in the English Catholic newspaper The Tablet, where he spoke of a disabled child whom he knew:

" *Nicky will never build a car, or fly an aeroplane, or balance a set of accounts. But he never stops producing joy and love wherever he goes. He is a year-round Christmas gift, however crumpled his wrapping.* "

That is a lovely, almost poetic, expression of the acceptance and recognition by one person of the uniqueness and giftedness of another.

However, not every person with a disability is a " year-round Christmas gift "! To pretend that they are dehumanizes the individual who, as a human being, is entitled also to

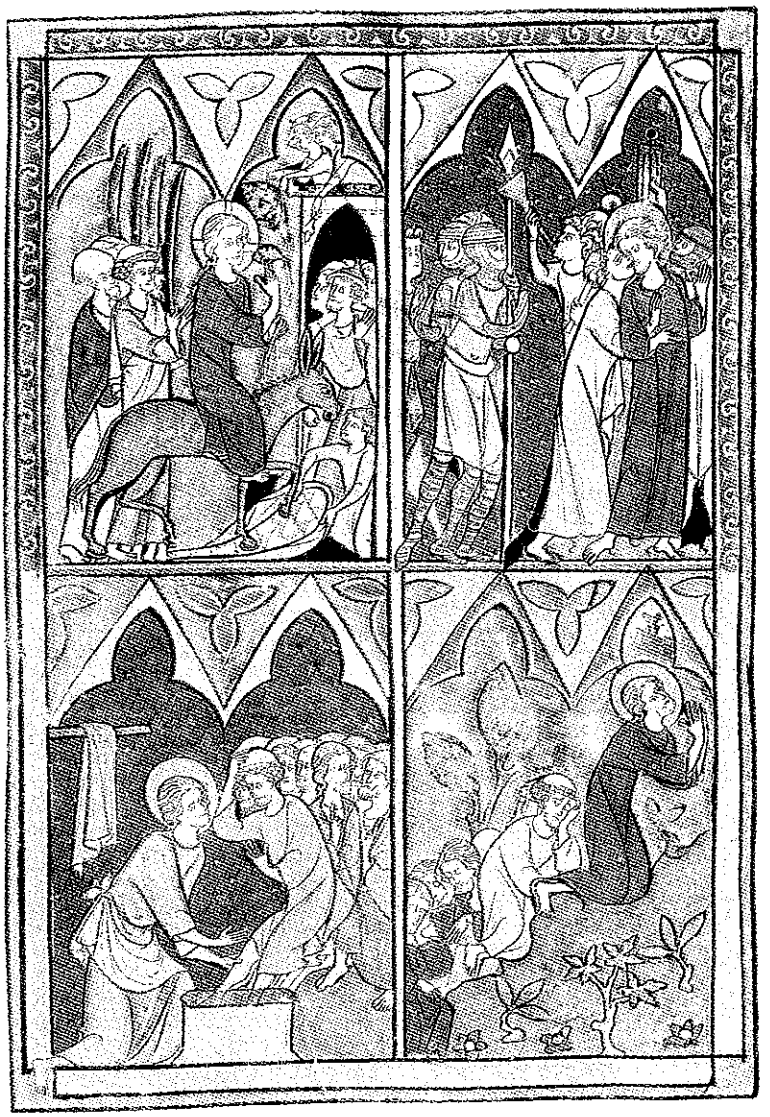
his or her defects and particular personality traits.

Persons Who Have a Learning Disability

I realise that this congress is concerned with the wide spectrum of disabilities experienced in human life and is not focused on any one kind of disability. However, my personal history, my training, and my experience with persons who have a learning disability inevitably result in what I say about the disabled referring mostly to that area.

Being the Prior General of an Order that deals with many thousands of persons who are physically, mentally, sensorially, and socially disabled, in more than 60 institutional and community services, you would expect me to be fully aware of Dr. Wolf Wolfensberger's principle of normalization in human services for disabled persons.

The commitment of our Order to "*keeping the sick and the handicapped at the center of our lives*," which we sum up in the one word slogan "humanization," is normalization given a more pronounced spiritual dimension.



Wolfensberger's "Assets Not Commonly Acknowledged"

In connection with the premise of this talk, Wolfensberger identifies some positive virtues, gifts, and dispositions of persons with learning difficulties that he calls, in the absence of an accepted collective noun, "assets."

I think, and will speak today, of those same positive virtues, gifts, and dispositions as "*enriching qualities*."

I want to acknowledge that in this part of my presentation I am drawing heavily on Wolfensberger's findings to make more specific how persons with disabilities enrich our lives.[4]

In developing this theme, I am not speaking as one who sees disabled persons as "holy innocents," with no defects and every virtue. My experience as a sibling of a disabled person, and as a teacher in special education, has left me no illusions on that point!

In enumerating what I call the "qualities" of disabled people, I am not suggesting that they are found in all disabled persons; neither am I suggesting that they are all frequently found in one person. In fact, some disabled people may possess few or none of them.

Nevertheless, the attitudes of disabled persons, in the main, are *more likely than not* to enhance and illuminate human relationships.

Enriching Qualities

Having made that disclaimer, I feel that I can go ahead and say that disabled persons have enriched my life and, according to my observations, the lives of countless others, by:

a) their special aptitude for concentrating their mental energies and other resources on the establishment, maintenance, and preservation of good relationships;

b) their natural and positive spontaneity, that is not diminished by social conventions;

c) their quick, generous, and warm response to kindly human contact, approval, and encouragement;

d) their relating to us as persons rather than according to our roles or functions in society;

e) their genuine and transcendent concern for others;

f) their capacity for being less conditional in their love for others;

g) their trust in others, even when it is not returned or justified;

h) their generosity and readiness to share what little they have;

i) their calling forth gentleness, patience, and tolerance from other people;

j) their uncomplicated enjoyment of life's gifts and pleasures;

k) their directness and truthfulness.

Let me stop there, because the listing of qualities or characteristics, no matter how " enriching " or germane, becomes tedious and, in the long run, self-defeating!

I would like to humanize the list by relating several qualities on it to real human experience.

Generous, Warm Response

Concerning the positive response of disabled persons to kindly human contact, approval, and encouragement, one result is that, quite simply, it is often a pleasure to be with them. In saying that, I recall my own 80-year old mother saying to me a few months ago, " I enjoy having Margeret home for a while from L'Arche—she's good company. " My mother and my sister have been good company for each other for some 57 years!

Connecting with Who We Really Are

When I claim that disabled persons often enrich us by connecting to whom we really are, rather than according to our roles or functions in society, I am remembering that when I visit my sister at L'Arche, her fellow residents are not the slightest bit impressed that I am superior general of an international religious order. They welcome me as Margaret's brother, who sends her all those post cards from many different parts of the world. If I had just come out of gaol, I would still be Margaret's brother and no less welcome.

Genuine and Transcending Concern for Others

Perhaps I do not have to justify saying that disabled persons often enrich us by the genuine and transcending concern they have for others, but Wolfensberger and Jean Vanier both have memorable stories that illustrate this point.

Wolfensberger reports an occasion when a man with learning disabilities was assigned the role of the haughty priest in a dramatization of the parable of the Good Samaritan (*Luke* 10:30-37). When the time came for him to walk uncaringly past the stricken victim, he was simply unable to do so and " stepped out of character " to begin succoring the " wounded man "

Jean Vanier sometimes speaks of a man with a learning disability who had trained long and hard in the hope of winning a gold medal at the Special Olympics. During the race one of the man's competitors tripped and fell alongside him. His reaction was not the " normal " sportive one of exploiting this advantage and racing ahead to win. Instead, he pulled himself up short and helped his fellow runner to his feet. Inappropriate behavior in a world of winners and losers, but how enriched we are as human beings by seeing or knowing of that selfless action.

Society Enriches the Lives of Its Disabled Members

The subtitle of this talk implies that there are two sides to the matter of lives being enriched in the interaction between society and its members who are disabled. As you will have noted, I have not spoken of the other side of the coin—how society enriches the lives of its disabled members. I feel that that question will be quite adequately dealt with by other speakers at this conference.

Impoverishment, Rather Than Enrichment

To speak of " enriching lives " in connection with the disabled reminds us that the reverse is possi-

ble. We can actually impoverish the lives of those members of society who are already confronting extraordinary difficulties in coping with life.

That can be done not only by the recognized means of neglect and isolation that will be spoken about at this conference, but also by more subtle means, such as the identification of people according to particular aspects of their physical or intellectual state that distinguish them as being different from what we consider to be normal.

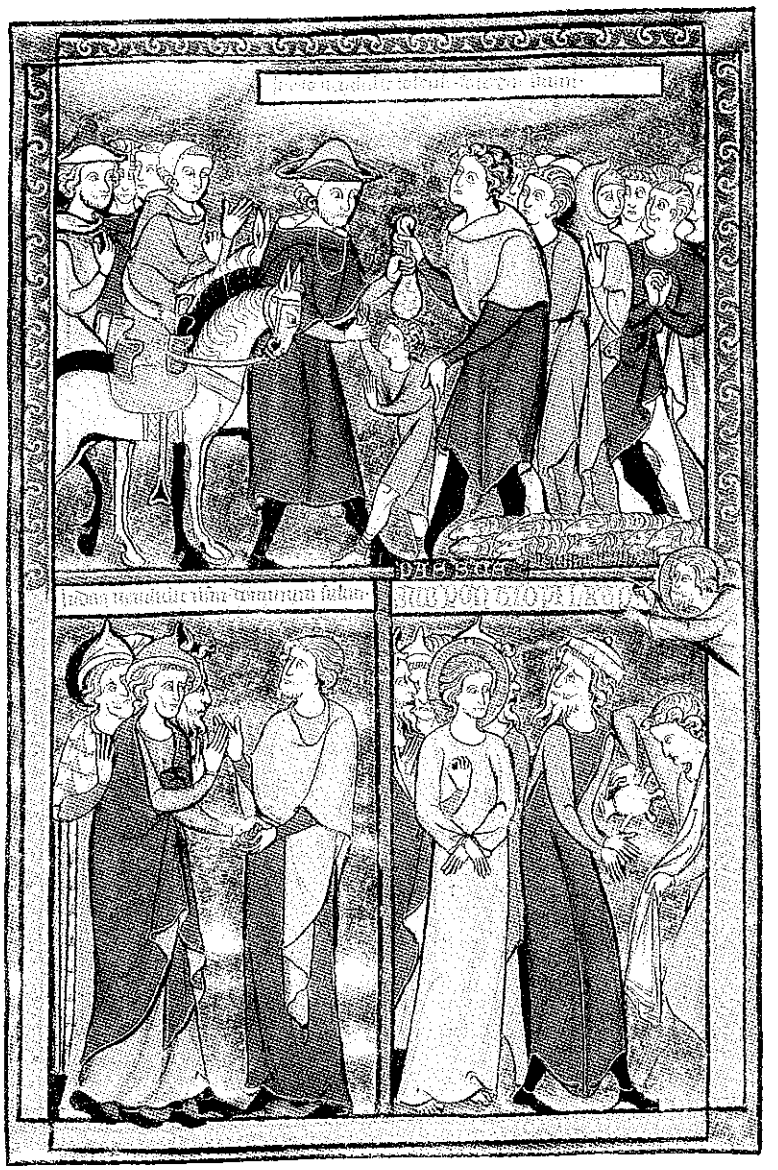
Policy for Life in Its Fullness

In that respect, I wish to state publicly the commitment of the Order that I have the honor to lead at present, to being more sensitive to the detrimental effect of demeaning terms and reactions directed at those it cares for.

That commitment was recently stated by our Irish Province in this way: " It is the policy of the Order to endeavor to avoid the use of labels, language, and behavior that demean the dignity of the persons within its services. The Order particularly wishes to continue the use of language and behavior that enhance the dignity of the persons within its service "[5]

The mutual enrichment of lives in the interaction between society and its members is nothing less than implementation of the vision of Jesus of Nazareth, who said that, " I have come so that they may have life and have it to the full " (*John* 10:10).

Father BRIAN P. O'DONNELL O.H.
Prior General Hospitaller Order of St John of God



[1] JOHN PAUL II, Southwark Cathedral, 28 May 1988

[2] Constitutions of the Hospitaller Order of St. John of God 1984, n. 42c

[3] JOHN HARRIOT, author of the " Periscope " column in *The Tablet* from 1975 until his death in 1990

[4] See WOOLFENSBERGER W., " Common Assets of Mentally Retarded People That Are Not Commonly Acknowledged, " published in *Mental Retardation, American Association on Mental Retardation April 1988.*

[5] Enriching Lives, *Policy Statement of the Irish Province, Brothers of St John of God October 1990, p. 4.*

DIRK J. BAKKER

Development and Social Effects of Learning Disabilities

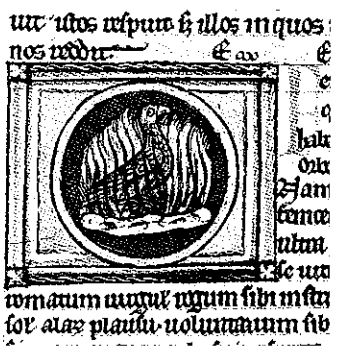
Learning Disabilities

Learning disabilities afflict millions of children and adults throughout the world and can lead to feelings of self-doubt, guilt, resentment, rage, despair, reproach, a general inability to cope, and sometimes even suicidal tendencies—in short, to emotional instability, depression, and social isolation. These disconcerting words were used by Dr. Thomas E. Bryant, Director of the US President's Commission on Mental Health, in his report to President Carter (Bryant, 1978). Similar implications for later life were reported by Dr. Otfried Spreen, Professor at the University of Victoria, Canada: " Not only do [learning disabled] youngsters suffer through a miserable and usually shortened school career and live a discouraging social life, full of disappointments and failures, they also have fewer chances for adequate employment and advanced training " (Sreen, 1987, p. 133).

What kind of children are we talking about? Psychiatrically disturbed, mentally retarded, perhaps, physically disabled children? None of these. We are discussing children who, at the onset of their learning problems, are in general physically, intellectually, behaviorally, and emotionally normal. At the outset, their sole problem is that they underachieve in scholastic ability, despite normal intelligence, appropriate schooling, sufficient motivation, and in the absence of gross emotional, sensory, and neurological disturbances.

Learning disabilities concern primary problems in the acquisition of spoken or written language, or in the acquisition of arithmetic: dysphasia, dyslexia, and dyscalculia, respectively. Learning difficulties secondary to other handicaps, such as attentional deficit disorder and hyperactivity, do exist but will not be the topic of my discussion. Neither will those deficits in learning be discussed that are due to poor education or school attendance.

The prevalence rate of primary learning disabilities ranges from 5-15% of the school population (Gaddes, 1980). In some countries, like The Netherlands, there are special schools for learning disabled children. In these schools, boys outnumber girls in a ratio of approximately 4 to 1. The most frequently encountered learning disability is dyslexia, a relative inability to read and spell. Again, this problem is a primary one, that is to say, not caused by another handicap, such as insufficient intelligence.



The aetiology and treatment of dyslexia will be discussed at some length. As to aetiology, the focus will be on brain mechanisms and anomalies that possibly underlie dyslexia. I will present two divergent, but not necessarily contradictory, aetiological models of dyslexia.

Dyslexia: Neuroanatomical Anomalies

The first model to be discussed is based on the neuroanatomical findings in dyslexic children as reported by Geschwind and Galaburda (Geschwind and Behan, 1982; Galaburda and Kemper, 1979; Galaburda, 1992). According to the definition of dyslexia, no gross neurological handicaps are involved in the disorder. However, evidence has recently emerged that neuroanatomical anomalies may underlie dyslexia and other forms of learning disabilities. The late Dr. Norman Geschwind and Dr. Albert Galaburda from Harvard University found numerous, so-called ectopias in the brains of deceased dyslexic persons. Ectopias are clusters of nerve cells that are dislocated in the brain. During gestation, nerve cells migrate from the interior to the exterior of the brain. Ectopias occur when migration is disturbed and cells fail to arrive at the appropriate destination in the

cortex of the cerebral hemispheres. Galaburda's neuroanatomical investigations revealed the presence of the ectopias throughout the brains of dyslexic persons. The majority of these ectopias were, however, found in the left cerebral hemisphere. The left cerebral hemisphere is, in most individuals, specialized in the mediation of language. Thus, one is inclined to conclude that ectopias in the left brain disrupt the development of language skills, that of reading and spelling in particular.

Another anomaly often found in the brains of dyslexic persons, which may be related to the emergence of neuronal ectopias, is symmetry of the so-called planum temporale. The planum temporale is part of the temporal lobes and therefore important for the subservience of language. Most non-dyslexic individuals show asymmetry of the planum temporale, the left planum usually being larger than the right one. The planum symmetry that is often found in the brain of dyslexic persons is due to the right planum's being too large. The excessive size of the right planum, according to Galaburda (1992), may be caused by a disturbance in a remarkable process that normally occurs during gestation, namely the death of a large number of nerve cells. Galaburda has suggested that in the dyslexic brain the disappearance of nerve cells is insufficient at certain brain sites, notably in the planum temporale of the right cerebral hemisphere. Thus, the right planum of the dyslexic brain may be largely made up of weak and poorly functioning nerve cells that send their equally poorly functioning connections to the left planum through the corpus callosum, the nerve fibers that connect the right and left cerebral hemispheres.

Reflecting on the possible cause of the anomalies found in dyslexic brains, Geschwind and Galaburda argued that these may be related to an excessive exposure to and/or to a high sensitivity for testosterone during gestation. This circumstance would have a detrimental effect on prenatal brain growth, particularly on the growth of the left hemisphere.

Geschwind and Galaburda were the first to demonstrate on a large scale neuroanatomical anomalies that possibly underlie the disturbed development of (written) language in dyslexic children. One must keep in mind, however, that this is still merely a hypothesis, since it has not yet been proven that the anomalies are necessary and sufficient conditions for the development of dyslexia and other learning disabilities.

Dyslexia: Brain Mechanisms

Another model on the aetiology of dyslexia attempts to describe possible brain mechanisms that underlie the disturbance. When reflecting on the development of the normal learning to read process, we (Bakker, 1990; 1992) came to the conclusion that learning to read proceeds in two stages. Initial reading relies heavily on the child's ability to discriminate between letters and word shapes and to differentiate left and right spatial relations. This assumption is based on the observation that novice readers are confronted with shapes that, contrary to the shapes of familiar objects, do not show constancy. When a six-year-old is shown a cup and asked to give this object a name, then the answer will certainly be " cup. " The same cup, shown in an upside-down position, will again elicit the response " cup. " Thus, the name of the object or shape remains unchanged, independenty of the spatial position of this object or shape. This phenomenon is known as object or shape constancy. Shape constancy does not exist for letters: a " p " that has been rotated may become a " d, " " b, " or " q. "

But letters are peculiar in yet another respect. When a cup is made out of soft clay and remodelled to a saucer, a six-year-old will certainly call the latter object " saucer. " However, remodelling " d " to a " D " does not imply a change in name. A similar perceptual complexity will be noticed by the novice reader on closer scrutiny of words and sentences: " mean " is different from " name, " " mane, " and " amen, " even though the same letters are used. The left to right arrangement of letters in a word is pertinent to the meaning of that word. The same holds for the left to right arrangement of words in a sentence: " he is at home, " " is he at home, " " at home he is " all consist of the same words but have different meanings.

Whereas text is perceptually demanding during early stages of the learning-to-read process, this is no longer so during later stages of this process. In advanced reading, perceptual analysis is automatized and, as Fries (1963) explains, is no longer a conscious process. The older reader has built up a lexicon and is able to use semantic and syntactic strategies in reading. Unlike the novice reader, the advanced reader, due to the generation of these strategies, can read fluently.

It seems likely that initial reading, due to the perceptual demands of text, is primarily mediated by the right cerebral hemisphere and that advanced reading, due to predominance of semantic-syntactic strategies, is primarily mediated by the left cerebral hemisphere. Thus, hemispheric mediation of reading may shift from right to left during the normal learning-to-read process. Indeed, the electrophysiological outcome of a longitudinal investigation (Licht, Bakker, Kok & Bouma, 1988) does show that initial and advanced reading are predominantly associated with right and left hemispheric activity, respectively.

Some children may not be able to make this shift and therefore continue to rely on right hemispheric reading strategies. As a result, they may develop a so-called P-type dyslexia, which is characterized by a slow and fragmented style of reading. Some other children may prematurely, or even from the very onset of the learning-to-read process, generate left hemispheric reading strategies. As a result, these children may develop a so-called L-type dyslexia, characterized by a hurried and inaccurate style of reading. Quite some evidence is available to show that P- and L-type dyslexia do exist; in other words, the P/L-classification is valid (Bakker, Licht, and van Strien, 1991).

It is not easy to assess to what extent Geschwind and Galaburda's neuroanatomical model and our neuropsychological model of dyslexia are compatible, if they are so at all. Galaburda demonstrated ectopias in both hemispheres of dyslexic brains, albeit predominantly in the left one. The bilateral distribution of ectopias is compatible with the existence of more than one type of dyslexia and other learning disabilities. It may be that a predominance of anomalies in one or the other side of the brain predisposes to the abundant generation of either right or left hemispheric reading strategies in dyslexic children.

Treatment

When it comes to the treatment of dyslexia and learning disabilities, it is hard to conceptualize how a therapy might be derived from the knowledge that neuroanatomical anomalies are responsible for these disorders. If one were to unequivocally establish that these anomalies are caused by an excessive exposure to testosterone during pregnancy, one might start to think of preventive measures.

The neuropsychological model on the aetiology of P- and L-type dyslexia is compatible with a rationale for treatment. P-dyslexic children, who presumably fail to make the shift from right to left hemispheric subservience of reading, should profit from (specific) stimulation of the left cerebral hemisphere. Stimulation of the left cerebral hemisphere is accomplished by the presentation of reading material in the right visual field and/or to the fingers of the right hand. The right visual field and the right hand project to the contralateral, i.e., the left cerebral hemisphere and vice versa. L-dyslexic children, who more or less skipped the phase of right hemispheric subservience of reading, should profit from specific stimulation of the right cerebral hemisphere. Right hemispheric stimulation is provided for by the presentation of reading material in the left visual field and/or to the fingers of the left hand.

Hemisphere-specific stimulation (HSS) is predicted to change the physiological activity of the stimulated hemisphere and, as a result of that, to improve (aspects) of reading and, possibly, spelling performance. A computerized program (HEMSTIM) is currently available to treat P-and L-type dyslexia by means of stimulation via the visual halffields (Moerland and Bakker, in press). A number of experimental, field, and clinical investigations have been conducted to evaluate the effects of the neuropsychological treatment (Bakker and Vinke, 1985; Kappers, 1992). In comparison with control treatments, the results are in general positive. There are children with severe dyslexia who, after treatment, appear to read (and spell) in a much better fashion. Unfortunately, however, some other dyslexic children fail to show much of an improvement after treatment. Thus, as one would predict, there are problems left to be resolved.

This conclusion is even more true for the types of primary (e.g. dysphasia, dyscalculia) and secondary (e.g. attention deficit disorder, hyperactivity) learning disorders that could only marginally be discussed in this address.

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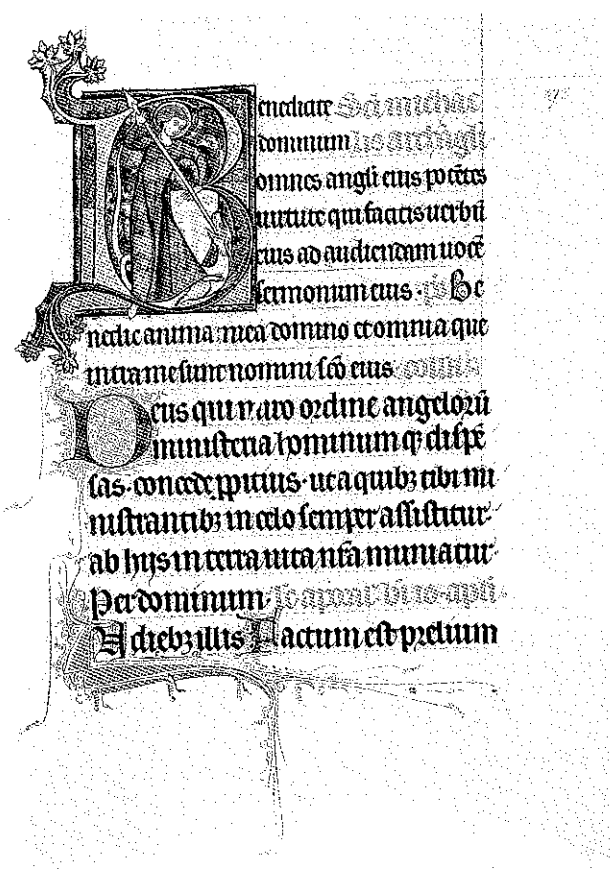
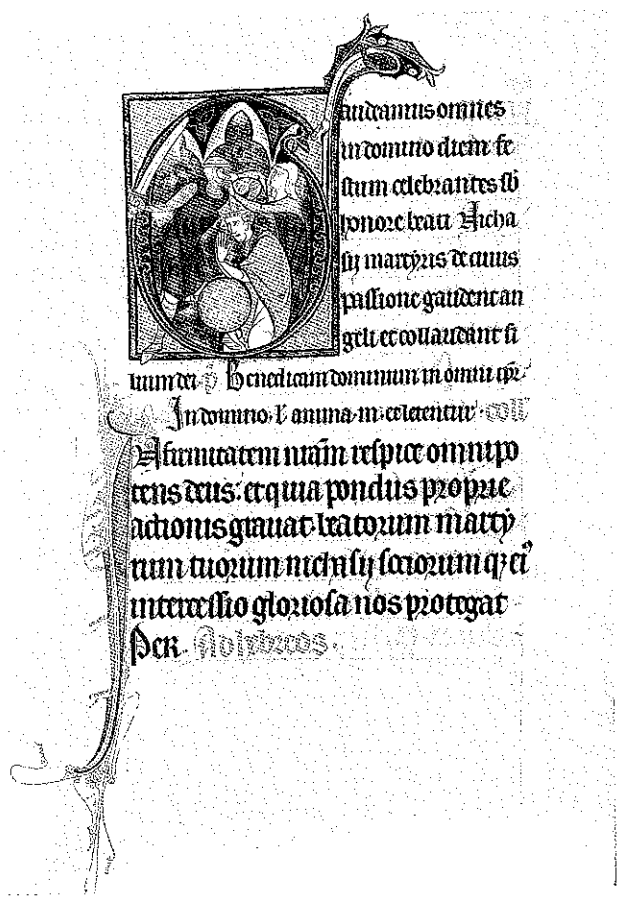




XAVIER RENDERS

Infantile Psychoses

Some people, perhaps, will ask whether it is appropriate to deal with the subject of infantile psychoses in a conference dedicated to the subject of disability. Nowadays, for many people, the word " handicap " has taken on a meaning which is limited to deficiency, to inadequacy, to the absence of something. This meaning is rather distant from the word's etymological origins—the game of " hand in cap " is a betting game which has two features: loss or gain, good luck or bad luck, things going well or things going badly. In horse races in England the handicap is a race where the horses which are thought to be superior are given an additional weight to carry or a further distance to run. Once again, there is advantage or disadvantage.

It seems to me that the approach to infantile psychosis can help us to to consider handicap not only in terms of what is absent. Indeed, still today, there is such an uncertainty about the definition, epidemiology, etiology, and treatment of psychoses that at a scientific level we are encouraged to have an attitude of modesty, on the one hand, and of dynamic research, on the other.

It is certainly true that psychotic children are " deficient " children—they have a rational and social life which is more limited than our own and we believe that they suffer. But their handicap, which is mysterious and enigmatic, leads us towards questions, inquiries, and research which involve new truths about human existence. This is why I am very grateful to the organizers of this conference for their invitation to read a paper on these children—their affliction, despite the burden it involves, renews our concept of handicap and enriches our thoughts and the action we take.

My paper will dwell upon four points:

1. The search for an integral model of explanation of a bio-psycho-social character.

2. Surprise, coherence, and creativity in different forms of instruction and therapy.

3. The psychotic child, his circle and society.

4. The psychotic child and himself—his suffering.

I. The Search for an Integral Model of Explanation of a Bio-Psycho-Social Character

1. Explanatory models of infantile psychosis remain very controversial and it is unwise to go beyond semiology—that is to say, a phenomenological description of the clinical pictures that we encounter. Furthermore, the very differences in these pictures make their grouping together very difficult. As a result, in scientific literature there are many different ways of categorizing infantile psychoses. To give an example, the serious disturbance known as autism, which is usually seen as a psychosis of early appearance, is now considered by many authorities as an instinctive structural psychosis.

2. Let us recall, in a very concise fashion, the main clinical manifestations encountered in most of the clinical pictures. But it should be emphasized that none of these symptoms is indicative on its own and that we can talk of psychoses only when a large number of psychoses are observed as being in a stable condition.

The central phenomenon of an infantile psychosis is depersonalization—that is to say, either an absence of the achievement of personality, or the dissociation of personality, or the division of personality.

The psychotic child is not able to distinguish well between the self and the nonself. Awareness of self and the world is altered. As a result, the behavior of this child is not merely inappropriate—his attitudes are incoherent, bizarre, or delirious.

His relational life is minimal: the child gives an impression of distance, of isolation. In his eyes, other people do not seem to be important. This can reach the point of a total absence of social contacts and to shutting himself up within himself, as is the case within autism. But, paradoxically, he can maintain a relationship of fusion with his mother or with another person. As a result, he is able to distinguish himself from this other person only to the smallest degree.

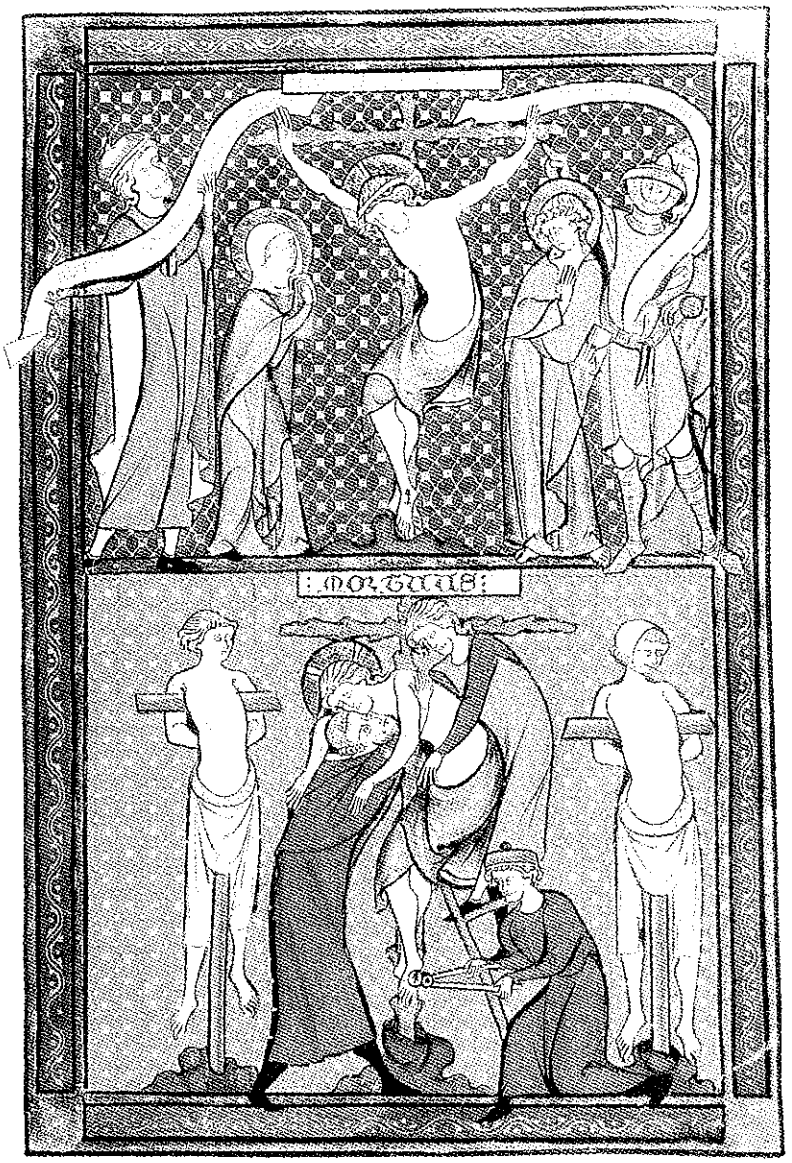
The psychotic child has a very low tolerance to change. If what habitually surrounds him is changed, his new environment becomes dangerous. Most of these children display developmental disharmonies. Certain parts of the personality are annulled while others are increased or remain as they are. In this way, for example, the child displays inertia in such elementary activities as getting dressed, but is very able and tal-

ented in drawing or in mathematical calculation.

Delirium is present in some cases, and this can be considered as being an attempt on the part of the child to express the external world or the discordant sensations which are within him through language or other forms of expression.

A feeling of division, of internal anarchy, which is experienced by many children, generates great anxiety. This provokes demonstrations of self-aggression or aggression towards the other children which are so sudden as to be scarcely comprehensible on the part of those people who surround the child.

From an intellectual point of view, whereas very often a basal intelligence seems normal, it can, however, not be used with ease in normal learning processes. It is something that leads to failure and stagnation at school and a widespread impression of intellectual deficit. In a certain number of cases, there are both deficit states and psychotization without the possibility of being able to ascertain whether the complication of a psychosis is present in addition to mental retardation, or whether the case is the other way around, or, again, whether these are unexpected signs of other causes which are still unknown.



3. We now come to the explanatory hypothesis. Two great currents of research and thought exist—one is based upon organicism; the other is of a psychological character. As you can well imagine, these two currents give rise to two very different routes involving treatment and care.

The model based upon the current of organicism sees psychosis as a psychosocial disturbance rooted in a somatic pathology. A cerebral malfunctioning caused by genetic, metabolic, or infective factors is emphasized or imagined to be at work. Some researchers respond to this kind of explanation with the observation that even if we are sometimes faced with a specific cerebral problem, there is no way of proving or establishing a relationship of cause and effect.

The psychological model finds exposition in a cloudy collection of different forms, ranging from the most radical to the most eclectic. It is based upon the idea of a deep disturbance of the construction of the personality caused by relational disturbances of the child with his immediate environment.

Often we are too categorical in our explanatory hypotheses of this kind. In giving exaggerated and generalized importance to the affective causes of the psychosis, starting with inadequate family relationships or unconscious problems of the parents, we have given rise to feelings of unjust guilt in a number of families.

4. Today, above and beyond declarations of general principle, we must nonetheless admit that the abyss which exists between these two currents is very deep. Neither of them really attempts to integrate therapeutic programs with the component elements of the thought world of the other.

With regard to my own views, I believe that we must make clear that we are very skeptical as to overly peremptory assertions. Each infantile psychosis is a case apart in which there are different component elements which have different weights and roles.

In the paedopsychiatric and social psychology wards of the University of Louvain we try to follow a bio-psycho-social model which seeks to integrate possible pathogenic and remedial contributions of the different factors involved, whether external or internal, organic or psychological, isolated

from each other or in a state of reciprocal interaction.

Similar models are productive in explaining the unleashing, the development, the cure, or the deterioration of all physical and mental illnesses and all the different kinds of handicap which afflict the human being. These models do not start with the assumption that every time there is a certain somatic dysfunction, a certain mysterious, deviant autoconstruction in the psyche,chism, a certain familial attitude, or a certain social environment which is at work to negative or positive effect. On the contrary, these models require the clinician to have an open mind and to consider and think about all the particular characteristics of the child.

I will give an example. The depressive attitude of a family may have contributed to the emergence of a psychosis in a child whose perceptual system was already fragile.

In contrary fashion, the attentive and stimulating attitude of another family can hinder the appearance of disturbances in a child who displays the same fragility. In other cases, again, the attitude of a family can be eminently adequate, but the perceptual fragility of the child in conjunction, for example, with a predisposition to anxiety or to mental deficiency, can inevitably create a psychosis.

5 I will finish this section by emphasizing those scientific ethics which support the putting into practice of an explanatory model of an integral character—ethics which accept uncertainty, are wedded to multidisciplinary open—mindedness, and, finally, give space to what every child and every family has which is unique and special.

II. Surprise, Coherence and Creativity in Different Forms of Instruction and Therapy

Given the short time that I have available, I would like to deal with certain key ideas relevant to the subject under consideration which in my opinion are of value as regards people afflicted by disability.

1. *Surprise*

In the field of psychosis it is especially dangerous to give an overly net diagnosis with regard to the development of the child. I would like to avoid giving you statistics on how these children develop—deficit tables, adult psychoses, partial improvement, or cure. We are not able to dominate the evolution of the psychoses and their aetiology. We leave the doors of surprise wide open.

One of my colleagues followed the case of an almost mutinous psychotic child and his family. One day a dramatic event took place —one of the legs of this child was crushed by a tractor that he had fallen under. A few days later, while he was in hospital, he began, for the first time, to general amazement, to express some sentences. How can this be explained? Were the anxious specters of the disturbance of the body which blocked communication weakened by a disturbance of the body which really took place? It would be rather presumptuous to make such a claim.

A tragic event which deprived this child of his leg gave him back speech and communication with other people. But I ask myself the question: would a similar reversal of the situation have taken place if my colleague had not dealt with this child, his family, and his relatives, with so much patience and perseverance?

2. *Coherence*

I have already stated that in today's rich countries there is an abundance of approaches, services, and methods of educational and therapeutic action. There is a great danger of lowering the psychotic or disabled person to the level of an object of notions and therapies that goes from one specialist to another, from one opinion to another, from one report to another. It is not unusual for a child or an adult to be literally submerged by different forms of treatment and re-education, in the same center or in different centers, which juxtapose each other, sometimes during the same day.

The utility of a form of help lies, essentially, in the motivation of the person who is responsible for it and in the therapeutic bond which is established. Lost in a net of people who are engaged in his cure, the psychotic child—like anybody else, and perhaps more so—loses interest and withdraws. We can well understand him.

Respect for his personality and ensuring that he is looked after hinge, I believe, upon two crucial points:

Have the people involved, whether they belong to the same or to different services, agreed on the priorities of the forms of help to be employed and are they prepared, if the need arises, to give up their own role either permanently or temporarily?

Have they asked themselves about the meaning that the help they have proposed could have for the young disabled person and his interests, if not, indeed, his request for this or that activity, his interest in this or that form of treatment or therapy?

From an ethical point of view, these two areas are no less important. Agreement among professional workers belonging to different disciplines implies—and I would like to emphasize this here once again—giving up a position of command and domination in dealing with and deciding policy towards the suffering person.

The paying of attention to the motivation and the requests of the psychotic child, even if at times one is coming up against the impossible, bears witness to the importance attributed to that person as a subject of instruction, of treatment, and of therapy.

3. *Creativity*

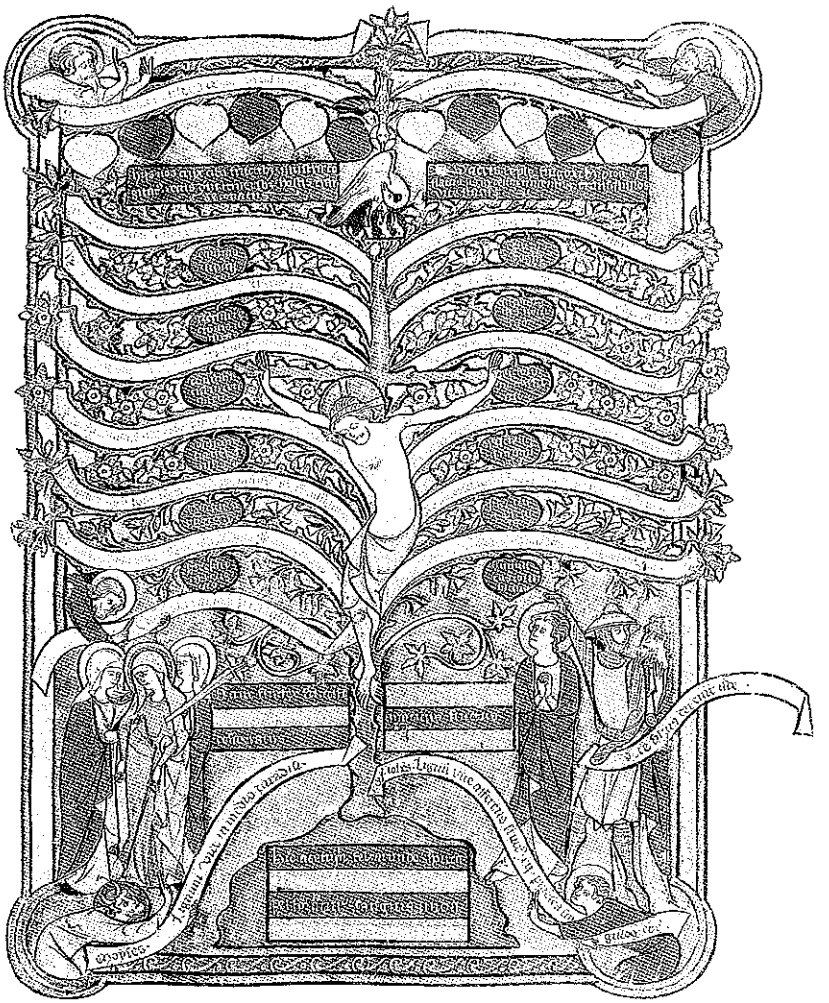
I defend imagination in all fields. Here are three practical ideas chosen amongst many:

An education which remains open to reality, true experience.

A wise process of schooling with the presence of forms of preparation, of a transition towards ordinary teaching, and support for the group of teachers. Brutal school integration should be guarded against. Care should also be taken

to avoid routine and stagnation in special teaching.

Diagnostic and clinical therapy teams which should not be too specific in their attitude towards this or that kind of child, thus avoiding the creation of separate procedures and approaches. Residential institutions should be open, as well, to different categories of sick or disabled people.



III. The Psychotic Child, His Circle, and Society

At this juncture, I would like to draw attention to two points:

1. Psychosis, which is more commonly called madness, is one of the border forms of human existence. We should not, therefore, be surprised if the psychotic child generates within his circle and social environment those feelings and forms of behavior which are themselves extreme and contradictory: attraction and rejection; feelings of being an outsider and desire for approval or domination; overestimation or underestimation of ability and capacity; a marked energy and then, at other moments, powerlessness, tiredness, and demoralization.

It is obvious that all these terms deserve comment and thought. What the psychotic child provokes in each one of us takes many forms, is of a subtle character, and gives rise to controversy.

Here I would like to emphasize the very great importance that should be attributed to help and support given to the parents and professional workers who take care of the child and who are often hit by the child's disturbances and try to employ paradoxical attitudes. It is no easy task to manage, by oneself, the emotions provoked by the experience of daily life with these children. Patient work on the part of the families and the teams must be envisaged.

2. I have already stated that the psychotic child lives out a fragmented identity. It is therefore of pre-eminent importance that a continuity is established, that bonds are forged, between the various people that live in his immediate environment, and in particular between his family context and his institutional context.

I remember a psychotic child that I had just admitted into a day center—for a number of weeks he kept his coat on for the whole day and took very little interest in what went on. We came to understand why this was. One evening one of us had a long conversation with his mother and she told us what leaving her son at the center meant for her. This child was not present during this conversation but the next day we found that he had taken his coat off.

A large number of disabled people who have had an intense relationships with their parents and who have not acquired a psychic individuality which is very secure are not able to form a bond with new people unless they are sure that they are not engaged in an emotional betrayal of their parents. It is therefore essential that these people are enabled to perceive the presence of a positive relationship or, at the very least, a relationship between those with whom they are connected.

IV. The Psychotic Child and Himself: His Suffering

How does the psychotic child live with himself? Is he aware of his handicap, of how he is different from other people? Does he suffer internally? How should this suffering be dealt with when it emerges?

These are difficult questions. Here we are coming up against the mysteries of life.

In view of his way of seeing things, threatening new situations and an excessive physical proximity can be dangerous. We may postulate that anxieties dwell within the psychotic child. His behavior, involving withdrawal and locking himself within himself, are often aimed at protecting himself from these fearful external intrusions.

At times, the psychotic child can be extremely lucid. He can say to us " My thoughts are mad " or " I am completely wrong. " This lucidity can, even if only incidentally, express itself in relation to others. Sometimes these children tell us extraordinary truths about ourselves. I make a forceful attempt to make this relationship of ours with the psychotic child and with every disabled person a spoken encounter between a nascent subject and another nascent subject.

From the outset, the human being draws sustenance from both words and milk. This is because his desire to communicate is very highly developed. Parents know this very well, and without asking themselves if the child understands them or not, talk to him, point out objects to him, and explain situations to him. They know that talking to a child and at the same time involving him in what is going on means allowing him to take part in the circuit of interaction. It means, therefore, recognizing him as a human being.

The question that the adult does not pose with the baby he nonetheless poses with the psychotic child, especially if this latter does not have access to active language: how much does he understand of what I am saying to him? Is it worthwhile to speak to him? Should I try to make him understand what I am saying to him?

My experience in this area of work over many years with children who are very seriously disturbed and who also do not speak has enabled me to discover that, like many of you, the fact of speaking to them in an unexaggerated fashion has the effect of not only being calming but of reducing fear levels, increasing their sense of well-being, and, in addition, making them turn in my direction and at times giving me a smile, or making noises, copied gestures, or signs that are equivalent to an answer. A relationship between humans thus comes into being.

It is certainly true that we know very little about the suffering of psychotic children and of that of each person who is afflicted by a mental handicap. Does this suffering not, perhaps, lie in an absence of meaning for external and internal events, in constant trial and tiredness, in a state of dependency for many, many things, in withdrawal in the face of failure, the anger at not being understood and, above all else, the look in other people's eyes?

But the moment he manages to make himself understood, if indeed he is listened to, the suffering is no longer only pain in the same way as the handicap is not only a lack of something. They can become the place and the opportunity for knowledge and truth.

As the medical doctor, psychoanalyst, and priest Denis Vasse puts it in his excellent book *Le Poids del la Souffrance*: " In being a place of speech, suffering must be understood as the cry of a subject who comes face to face *both with death and the desire to live*—the cry of a subject being born. " We are tempted to add to the fine phrase of Freud, " As long as man suffers, he can still continue his journey on the earth, " the thought that he should do so as long as he finds in this meeting a recognition of his truth.

Rev XAVIER RENDERS
Director of the
Infantile Psychiatry Bureau
The Catholic University
of Louvain, Belgium

VIRGINIA J THORNBURG

That All May Worship

Your Eminence, please accept our thanks for this unusual opportunity to meet as children of God to discuss the unique gifts and needs of people with physical, sensory, and mental disabilities. We come from diverse countries, with varying responsibilities, experiences, and faiths. We come to this Holy City, the Vatican, to learn, to teach, to celebrate, and to stimulate. We come to help create a more caring and just society for persons with disabilities and their families *everywhere*—a world of possibilities and promise rather than a world of anger, alienation, and waste.

I speak to you this afternoon as the mother of Peter, a man of 32 years, who was seriously brain-injured when he was less than a year old. Tomorrow afternoon, at about this time, Peter's father, my husband, Dick Thornburgh, will also address this Conference.

Through this one man, my son Peter Thornburgh, whom the world regards as intellectually quite limited, two parents have come to care in amazing ways and to speak out on behalf of persons with disabilities, whenever possible.

For Dick and for me, it has been our faith that has strengthened us in our family responsibilities and motivated us in our work. I sense the same is true for most of you. It is almost impossible to imagine life without the cornerstone of faith. And yet for many people with physical disability, chronic illness, blindness, deafness, or mental disability of any kind, it has been difficult, if not impossible, to enter the church and to learn of God's love—much less to access a full life of faith.

Let me restate this proposition even more strongly. People with disabilities, who are clearly loved by God, have often not been able to hear God's word, to see God's glory, or to feel the healing warmth and affirmation of God's community of faith. This exclusion, unintentional in most cases, has caused people with disabilities to feel marginalized in the very places where love and justice are preached and practiced.

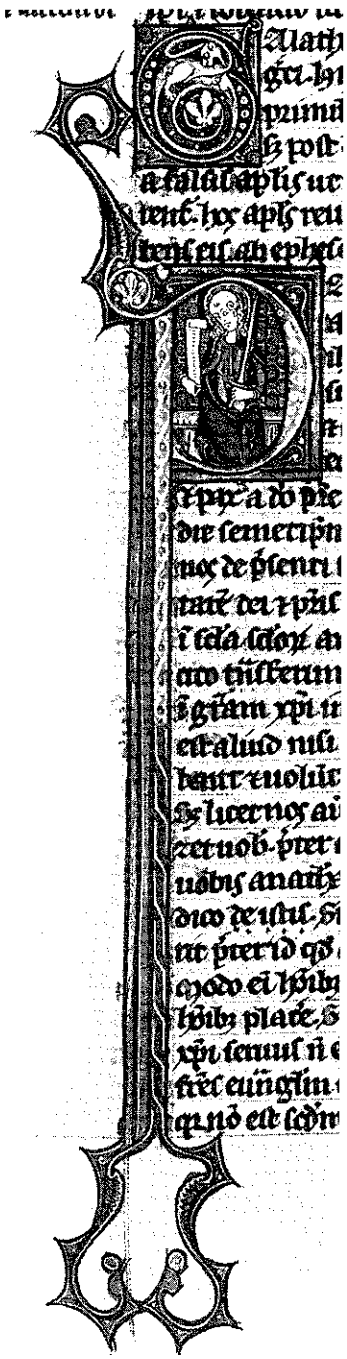
For centuries, the Church has prayed solemnly and eloquently for the sick, the lame, the halt and the blind, the deaf and the demon-filled. But praying for someone, or a group in the abstract, is quite different from creating caring congregations where the gifts and talents of people with disabilities are welcomed and used.

Let me return to the example of our son with mental retardation. While some in his church may regard him as tragic, others view him as good company and a hard worker. Within his congregation, Peter has been responsible for assisting younger children, straightening hymnals after the services and filling the speaker's water glass. Peter is reluctant to miss church, believing, I suspect, that God needs him to lend a hand every Sunday. Peter has come to believe that he is loved by the people of his church as well as by God. Oh, that we all could have such an affirming experience!

The Gospels speak movingly of Jesus as He lived among, loved, and blessed those who were vulnerable. In fact, the miracles of internal and external healing were generally extended to men, women, and children whom we now call people with disabilities.

My favorite New Testament disability passage, found in the Book of Luke, himself a physician, describes a man with paralysis who was determined, absolutely determined, to see Jesus. Undaunted, he enlisted the services of four friends, folks just like you and me, to carry his bed through town to the house where Jesus was speaking. These friends became caught up in his mission, despite the awkwardness and physical strain of the task.

As they carried his sickbed through dusty streets, 2000 years ago, these four friends surely were the target of scornful laughter.



Upon arriving at the house, it became clear that entrance would not be easy. All doors were blocked with people listening to Jesus and seeking his attention. Even the windows, an alternate form of access, were obstructed. What to do? Was this man, whose faith and friends had carried him, to be denied the chance to be healed by Jesus?

Fortunately for all of us who are concerned about people with disabilities, the story ends on a positive note. The friends did not abandon the man with paralysis when the situation appeared impossible. They used their God-given imaginations, lifted him up to the rooftop, cut a hole in the roof tiles, and lowered him down into Jesus' precise presence! The rest is history. The faith of the man and the constancy and problem-solving assistance of his friends were sensed by Jesus, and the man was miraculously healed. Note that this healing required both the man *and* his friends. That's where you and I come in.

Are we willing to assume inconvenience, scorn, and possibly hardship so that someone dear to us, or even someone whom we have never met, has access to a full life of faith?

Think of it in yet another way:

To be prevented, because of disability, from entering and serving in God's sanctuary should be unthinkable. To give up, because of disability, the goal of becoming a priest or minister, should be unthinkable. To be denied, because of disability, the healing, cooling, uplifting waters of faithfulness, should be equally unthinkable. To speak directly, who among us has the right to tell another person, by action, word, or unwelcoming attitude, that they are not worthy enough to worship and serve God? No person, no group of people, has the right to exclude another from worship.

Over an extended period of time, I have talked in depth to people with a variety of disabilities. I wanted to learn about their spiritual journeys. I wanted to learn whether their churches had welcomed them, assisted them, empowered them, and allowed them to use their gifts for God's glory.

— Some were wheelchair users who, because of steps and narrow doorways, were unable even to enter their churches.

— Some were people with unclear speech who were treated as if they were intellectually limited when, in fact, they were often quite gifted.

— Some were older people with failing vision who, because of poor lighting and lack of railings, felt unsteady and unsure within the church.

— Some were people with mental illness who could hear God's call but were told, when at worship, to " quiet down, " " behave, " or " be gone. "

— Some were people too ashamed to tell anyone within the community of faith about their cancer, AIDS, epilepsy, learning disability, or psychiatric disorder.

— Some were people with hearing loss or deafness who missed God's word because of antiquated sound systems or a lack of sign language interpreters.

— Some were people like my son, with limited theological book learning but with profoundly uncluttered faith, who were treated with condescension and pity.

Christ's church is called upon to affirm and enrich, not to cause feelings of frustration, indignity, and shame.

The church, bearing Christ's name, is called upon to be a place of welcome, justice, and love; a place where all of us, with and without disabilities, are accepted, without reservation, *as we are*: a place where our gifts and abilities are recognized and used.

It matters not whether our own church is located in a small rural village near the Sea of Galilee or in a metropolis on the banks of the Tiber, the Neva, or the Nile. We have work to do. It matters not whether our church is modest or a grand Cathedral. We have work to do. It matters not whether our church is presently excluding one person with disability or one hundred. We have work to do.

Our work begins by listening to people with disabilities, listening to

their concerns and complaints, and listening to their ideas about how the church can become more welcoming

Some of the needed changes, they will tell us, involve architectural or structural revisions—the addition of ramps, curb cuts, parking spaces, wider doorways, accessible bathrooms, and elevators. These changes will not just benefit people with disabilities. They will assist mothers and fathers with children in strollers, delivery men with heavy boxes, millions of us who are older as well as people of faith who use wheelchairs, crutches, walkers, and canes.

We must not let cost factors dictate whether or not to proceed with these changes. Once the church decides that *all* of God's people can and should be full pariicipants, once that intention and commitment is sure, the funding will follow. Trust God in this and in all other things.

Some of the needed changes will assist people with sensory disabilities, people who are blind or deaf.

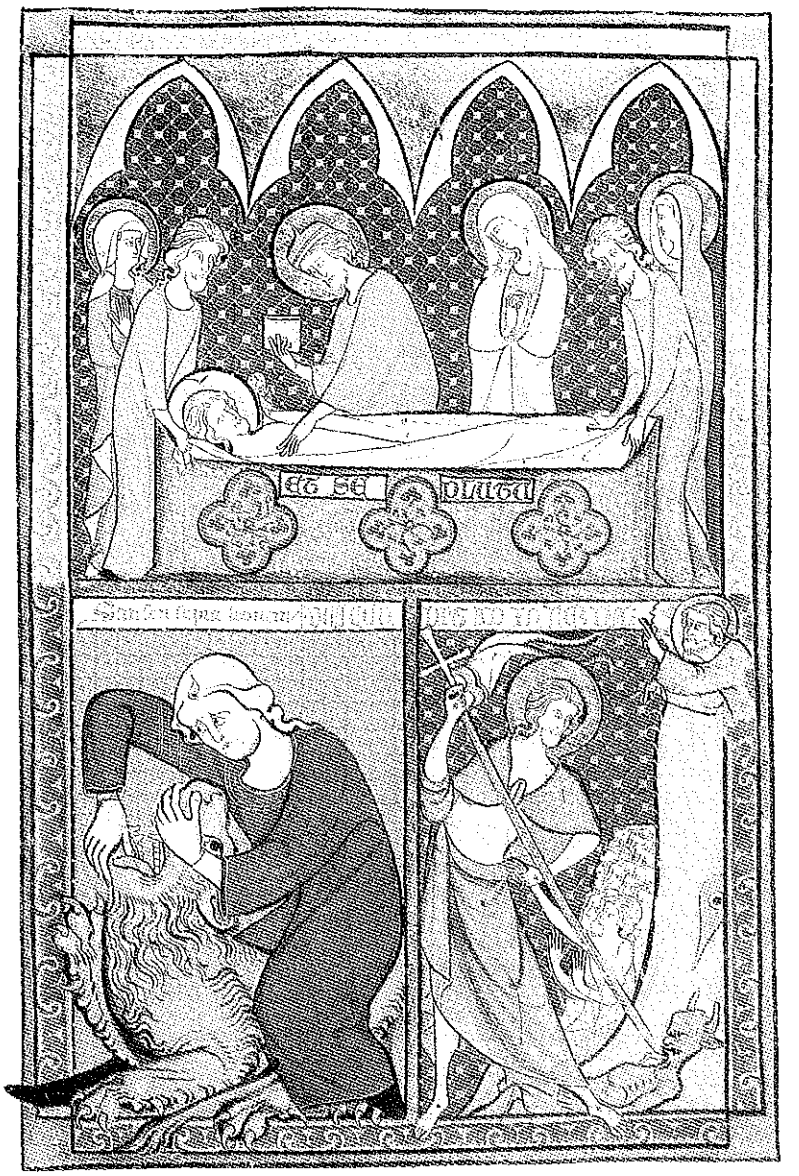
For people with visual impairments, large print, taped or Brailled Bibles, missals, prayer books, and hymnals are now available in most countries. In addition, the lighting in most of our churches can be improved so that all of us read more easily and feel less anxious near stairs and in darkened areas.

People with hearing impairments also deserve better accommodations including improved sound systems, assistive listening devices, and sign language interpreters.

Finally, changes are needed in our attitudes towards people with disabilities. No challenge is more important than this. Necessary changes of mind and heart will occur only if we educate ourselves about conditions that up to now have been discussed in hushed tones.

Through education and prayerful commitment, we can replace stigma with support, pity with empowerment. We can come to realize how alike we all are, with and without disabilities, in our fears, hopes, and dreams as well as in our desire to use our gifts within the church.

Just imagine this:



A church where the person carrying the cross in procession is ayoung man with Down Syndrome.

A church where someone who has faced a serious psychiatric disorder can lead a discussion in the adult education class about their experience.

A church where isolated, lonely older members are transported to and from worship.

A church where the altar and choir area are ramped.

A church in which the Christmas pageant includes an angel with cerebral palsy.

Welcoming congregations, like these churches, could set an example for us all. Permit me to close my remarks by reading from a prayer found in the handbook *That All May Worship*, which you have already recieved.

Let us pray for all God's people.

For people who are blind and cannot see, and for those who can see but are blind to people around them.

For people who move slowly because of accident, illness, or disability, and for those who move too fast to be aware of the world in which they live.

For people who are deaf and cannot hear, and for those who can hear but who ignore the cries of others.

For people who learn slowly, for people who learn in different ways, and for people who learn quickly and easily but often choose ignorance

For people who have chronic illnesses for which there is no known cure or relief, and for people who live in unholy fear of developing a chronic illness.

For families, friends, and caregivers who serve people with disabilities, and for those who feel awkward in their presence.

For people who think they are worthless and beyond your love, and for people who think they don't need your love.

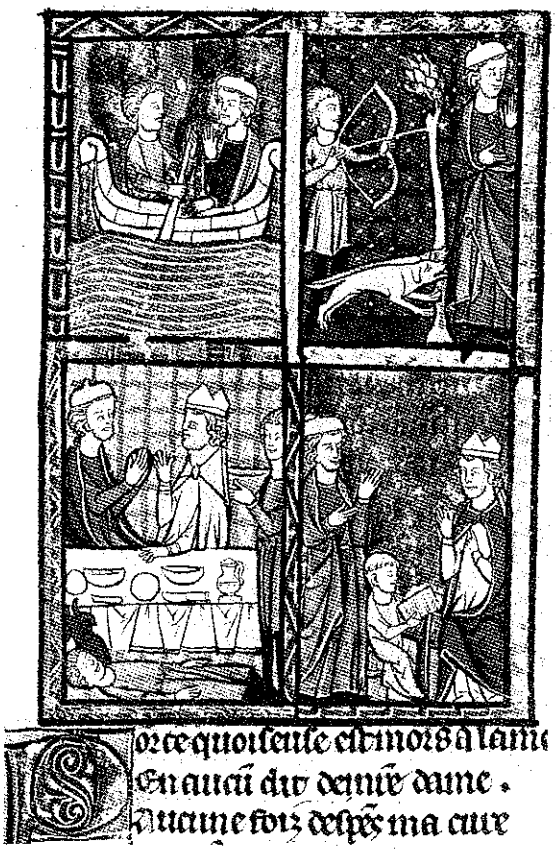
For people who feel isolated by their disabilities, and for people who contribute to that sense of isolation.

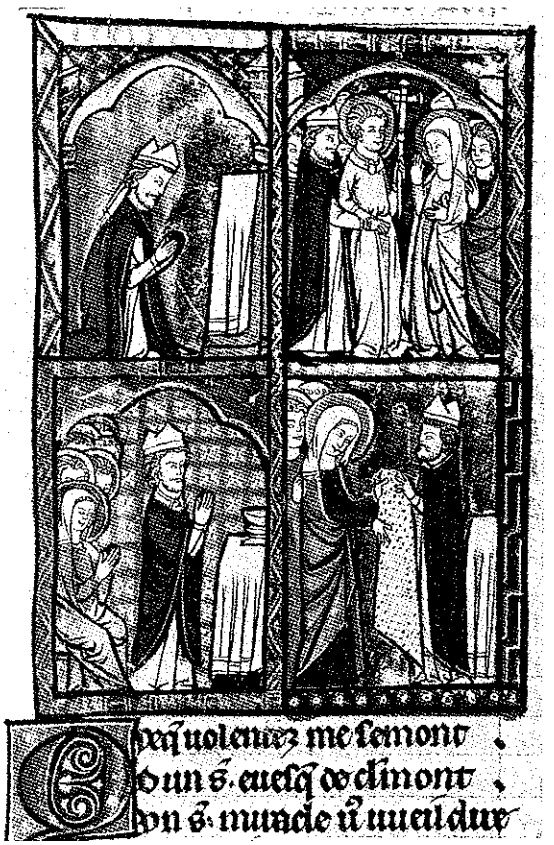
For all the people in your creation, that we may learn to respect each other and learn how to live together in your peace.

In the name of Jesus Christ, our Creator, Lord, and Comforter.

Amen.

Mrs VIRGINIA J. THORNBURGH
Director, Religion and Disability Program
National Organization on Disability
Washington, USA





ALBRECHT FREIHERR VON BOESELAGER

Pilgrimages for Persons with Disabilities

It is an honor and also a pleasure for me to be able to speak to you on the subject of pilgrimages with persons with disabilities and I must thank you for this opportunity. At the same time I have to admit from the start that I can hardly do adequate justice to this theme in such a short time. Once a year for over 20 years I have accompanied people with disabilities and chronic illnesses on trips to Lourdes. Again and again new and significant experiences were the result, and my own life has been changed decisively as a consequence.

Allow me to make three remarks before I begin:

1. The background to this talk is based on pilgrimages made to Lourdes. There are many other pilgrim's resorts, also for people with disabilities. However, Lourdes, which is specialized in accomodating the invalid, seemed to me the most suitable to make certain things clear.

2. My point of view and my practical experience are as a helper and companion to the people with disabilities, and I can only speak from this perspective.

3. The insight and personal experience of such pilgrimages are so demanding that I can think of no participant who was able to remain unmoved.

At the same time it is hardly possibile to put what happens there into words. So I would like to invite you to accompany me in your imagination on such a pilgrimage and attempt in this way to get at the heart of the matter. Some things will naturally have to be brought under a special focus.

And the last preliminary remark I would like to make, is to ask you to start our attempt with a short prayer. Since a pilgrimage is essentially an encounter with God, and prayer is the crux, our mutual attempt to go on a journey of the imagination can actually only succeed if it is made under the sign of prayer.

What is at the beginning of a pilgrimage?

At the start of a pilgrimage it is first of all the departure that absorbs so much energy. Every long trip needs more or less extensive planning. This is all the more the case when it is planned for persons with disabilities and chronic illnesses. The problems of transport and provisions alone need enormous preparation.

And yet it is chiefly fear that governs each pilgrim on the platform of the railway station when he meets his still unknown co-travellers and their assistants. More than the healthy, those with disabilities and illness are dependent on a regular routine and reliable care, since they cannot master the world on their own. And now they need more than normal help; they must surrender themselves to others to whom they are bound for the duration of the pilgrimage. Fear of having overstepped the limits of one's own courage often arises now, as well as the question whether going on this pilgrimage wasn't a mistake. Behind these thoughts is probably an apprehensive doubt: will hopes remain unfulfilled? Will the traveller return home feeling betrayed and have to submit to the mockery of those who with a great amount of energy had tried to talk him or her out of the pilgrimage in the first place?

What leads to the decision to go on a pilgrimage?

It is previous pilgrimages or accounts by other pilgrims that most often lead to the decision to go on a pilgrimage. Sometimes in the young a lust for travel and adventure plays a role. The greatest and commonest incentive, however, is the longing for support, for a restorative, perhaps even a cure—a longing born from disablement and affliction. Whether it arises from a deep and trusting faith or from a desperate hope to try a pilgrimage when other things have repeatedly failed—in any case it is an encounter with God and His love, something perhaps only vaguely realized.

It is for this that the pilgrims have left home, have found the time, and now at the beginning of the journey lie or sit in an uncomfortable train, lacking fresh air, and possibly under an increasing amount of pain.

It is a somewhat different situation for the accompanying helpers. For many of these helpers it is not the direct search for God's intervention that has led them on this pilgrimage but, on the contrary, the will to help those who are dependent on them. But they, too, often enough have anxious thoughts: will they be able to withstand the physical strain and, even more, confrontation with the massive urgency and

moving destinies of those afflicted with handicaps or illnesses.

At this point, you are reminded of Abraham, who, following God's call, set out from his tribal land to trek to Israel, or of the people of Israel on their march through the desert. Neither the destination nor the fulfillment of the journey are within reach.

What is therefore necessary at the beginning of the pilgrimage?

From the very beginning much depends on how the team of helpers succeeds in creating a feeling of trust through friendly care and through verbal exchanges and how, by their good preparation and organization, they succeed in transmitting a feeling of security. The first devotions and Mass take place already during the journey and lay the groundwork for an atmosphere of prayer. By the time the pilgrims have reached their destination, an initial layer of confidence has been established, and a pilgrim's company has formed, in which important threads of conversation have already been woven. The mutual getting-to-know-you phase has encouraged many to tell their stories and express their hopes and disappointments. This atmosphere of understanding and confidence, the basis for making such conversations even possible, are a real surprise to many.

What happens after the destination is reached? Where does one arrive?

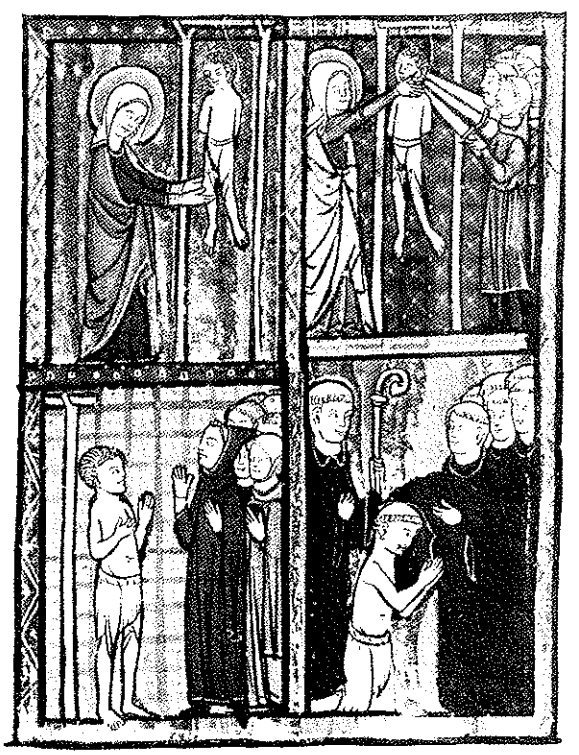
Once the destination is reached, the situation changes. The geographical goal of the pilgrimage is at hand and the inner journey shifts into a new phase, which in some ways resembles the disciples' journey to Emmaus. Whether it is expressed or not, God is present in word and thought at least as a subject of conversation or observation until the direct dialogue with Our Lord can begin, often for the first time, and then can be taken up, continued, and amplified.

Lourdes is, like many pilgrim's resorts that cater to the sick and persons with disabilities, dedicated to Mary. "Healer of the Sick," and "Comforter of the Desperate" are two of the many honorific titles given to the Mother of God. There are few regular occasions where the reality of these attributes of Mary are experienced more clearly than on pilgrimages to Lourdes with the sick and the lame. In this capacity she is referred to by Christ on the cross as Mother of the Church and of Christians. The atmosphere of the pilgrim's resort is infused with trust in this Mother and with acceptance of her motherly care. She guides you on the path to Christ and to God the Father, to an intimation of an experience, or perhaps even to a resolution of one's own personal plan for salvation, which God has foreseen for the sick and lame in His own special way.

Meanwhile the outward impressions of the pilgrim's resort and the solemn daily routine take over. These are the extraordinary experience as a person with disabilities of being the center of attention, the experience of this large company of sufferers, often with comparable or even worse lots in life, and all in an atmosphere blessed by the perceptible peace of God and a general willingness to help. The pilgrim's resort seems to exist in another world that is somehow—despite this concentration of misery and through the proximity to God—a more sanctified world. It transmits the message that God in His goodness and mercy to the fallen and sinful world always and, here-and-now, concretely offers salvation, the eradication of sin and suffering at their very roots.

What developments and processes do the persons being cared for and the helpers experience?

All too often the question of the physical miracle, of the spectacular cure, is the main interest. Undoubtedly such miracles do occur. They are important as signs and often the visible initiation of a special vocation for the person thus healed or for the ones who witness it. But they are few and far between compared to the vast number of sick and persons with disabilities. If the pilgrimage were solely aimed at such results, it would end in most cases in abysmal disappointment. On the other hand, it soon becomes clear that an inner strength is given—the power to persist despite undiminished and continuing pain



—and a new meaningfulness found in one's own outwardly-confined life. The less spectacular miracles are the visible seals of such confirmation.

The daily routine after arrival remains a strenuous one. The many strong impressions cannot all be immediately coped with. Many will become accessible later and only gradually. Holy Mass, the sacrament of penance, and the annointing of the sick are experienced as offers of grace and accepted with deepest gratitude as pledges for the future.

Last of all, it is the Church's experience with suffering—her ability to transmit this charism to the sick and disabled pilgrims who turn to her and to take this up in her liturgy—it is this experience that stamps and upholds such a pilgrimage. It is these moments in which the Church is known not as lame and vulnerable but as all-powerful, not in the sense of an institution of power but as a community that with the might of Mary leads to God the Redeemer.

For the helpers who accompany the persons with disabilities, the experience with these pilgrims is profound. If many just went along only to help out, they soon see themselves confronted with the immediacy of not being able to avoid either the events of the pilgrimage or the burning question of God. They will not return home the way they left it. Either they say " yes " to what they have lived through, gain a stronger belief, and set out on the road to a new and deeper faith or they begin to set up barriers. A neutral stance of being unmoved is out of the question in the face of their deep personal contacts with the pilgrims with disabilities and the way the changes in these pilgrims are manifest.

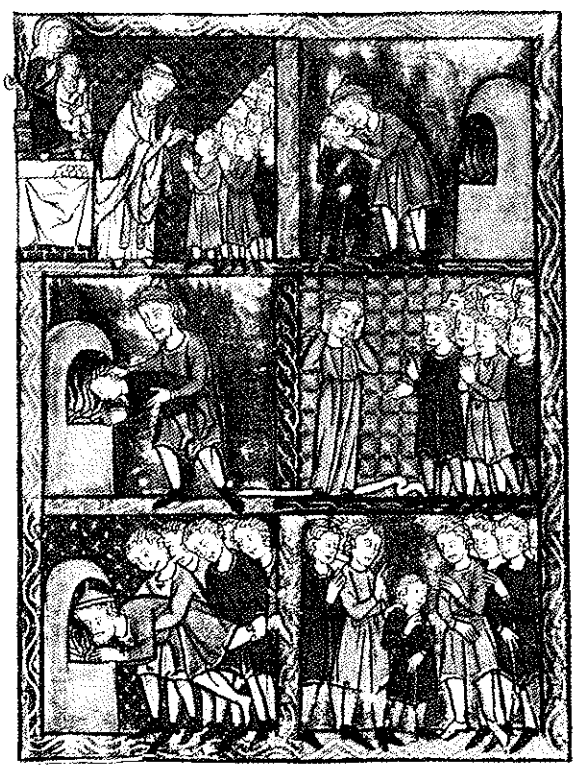
It confirms the lines from Matthew 25 in the Bible: " .. As you did it to one of the least of these my brethren, you did to me. " God accepts their readiness to help the helpless as a service to God and meets these helpers who assist the sick and the disabled head on. As a reaction, they often feel powerless and no longer want to accept the gratitude given them by the pilgrims for their readiness to talk and to listen. For now the helpers are more and more aware of themselves as just as much given to as giving to those they came along to help.

It is felt as an enormous deliverance, for instance, to push aside the pressure of one's own problems, which become relative when faced with the overwhelming lot of the pilgrims with disabilities and chronic illnesses and their obvious gratitude and joy. The tangible healing power of God strengthens these assistants' trust in Him. The sick and disabled pilgrims become for them a living gospel so powerful that it can make the life of these helpers take a new turn.

The sick, of course, become aware of this effect and aware that they themselves are more or less responsible. This makes them feel important and accepted. Our Holy Father in his Apostolic Letter *Salvifici Doloris*, on the Christian meaning of human suffering, revealed the mystery of pain to be the source of a great reconciliation. For me this is one of the greatest wonders, how the pilgrims with disabilities and chronic illnesses are suddenly enlightened as to the meaning of their infirm lives, how they accept this and take strength and comfort from this. And by their acceptance of suffering allow this to bear fruit within the Church itself. Our Holy Father says that the Church is constitutionally built on just this happening.

Herein lies the almost frightening responsibility for planning and carrying out such a pilgrimage. Will it succeed in creating the atmosphere for such an experience that perhaps in quite rare form allows the persons with disabilities to recognize the sense of their suffering and to accept it, thereby making their lives fruitful for the world? Or will this chance be shut off by mistakes, by clumsiness, maybe by a superficial and obtrusive way of talking about the mysterious meaning of life?

Luckily, once again God Himself takes the willingness to go on a pilgrimage as reason enough to help out here.



How does the pilgrimage end?

When the pilgrimage is at an end, the fruitful results become more and more evident on the return trip. Very seldom have I found that the pilgrims with disabilities have been disappointed, even if they gained something different from what they had expected or hoped.

One of the pilgrims had completely forgotten how to ask for something, because at home it was useless to do so He then also stopped asking God for anything. The outgoing and cheerful helpers gave him back the confidence to request things again. When someone formulated for him his own wishes to God, he then rediscovered for himself how to direct his innermost pleas to God and to trust in the fact that these wishes would not go unheeded. It was like being given a new life.

Another pilgrim lived in oppressive resignation in the face of his joyless fate as a handicapped invalid. Every memory of happy times was buried. At one of the services he was struck by a word. He began to speak to his sick roommate about it and, encouraged by him, he received the Sacrament of Reconciliation. This paved the way for him to find his own meaning in life

Another pilgrim, who often went on pilgrimages and had a deep and trusting faith, found new strength in prayer and a renewed belief, as he had the last time. The annual pilgrimage is for him like a service station: he fills up on faith for the coming year.

" Lourdes changed my life " is an oft-repeated statement. This is manifested in the numerous charitable activities that are taken up once home. Speaking for the Order of the Knights of Malta, I can say that its effectiveness would be unthinkable today if this source did not exist.

Also the priest who goes along on the pilgrimage is strengthened in his pastoral duty by what he experiences. As well as the accompanying doctor, who has experienced some things which bring him closer to his vocation as " medicus alter Christus. "

And, despite everything, the pilgrim's company made up of the persons with disabilities and chronic illnesses and their helpers is mostly a cheerful lot. " I haven't had such good laughs in years " is one of the greatest compliments and, fortunately, not an all-too-rare one.

Taking leave of the company at the hometown station is then all the more difficult. Many tears of farewell make clear that close personal relationships have been formed. They speak for the fact that the difficulty of returning to everyday life has not been abolished. But they also speak for the happy moments that convey new strength for mastering it

In the end everyone, also the Church and the world in which the Church is effective, is the richer.

What remains after the pilgrimage?

I would like to add only a few key words to what remains after the pilgrimage and what has already been mentioned in my talk. New personal relationships which are founded on mutual religious experiences. A new understanding of one's own remaining physical or mental wounds and deficits under the impression of the nevertheless healing encounter with God. The courage for taking up a new road again and again out of the difficult or comfortable daily round in a small or big way to follow in God's footsteps. Renewed confidence in faith and the Church.

ALBRECHT FREIHERR von BOESELAGER
Hospitaller of the Sovereign Military Order of Malta

THOMAS F CRIBBIN

Affirmation for a Change

From the title of today's presentation it is urgent that we examine two areas of concentration, namely, change and affirmation.

Each of us knows the wide and multidimensional impact of disability or any type of catastrophic illness. It affects us physically, emotionally, psychologically, spiritually, and socially.

This " total immersion, " if you will, becomes a major focus of our lives. All of us who have faced a life-threatening event understand what a " liminal experience " creates in our personal lives. We reach a point when the ailment is at a peak, when the operation with all of its anxious anticipation takes place.

We reach a crescendo when all of our life is changed, where nothing will ever be the same again

The nodding heads and the knowing smiles are testimony to the life experience of many who are here today

In the New Testament, Mark makes us aware of a man who had felt the experience which we call " liminal. " He was totally paralyzed. Though paralyzed, he had four friends who carried him to see and to meet Jesus.

Imagine their disappointment when they arrived at the house where Jesus was—to find there was no available space. No possibility of entering through the door. As Mark says, " The house where he was staying was so packed with the visitors there wasn't room for a single person more, not even outside the door. " We have all been in situations where we have been locked out, where we were last on line, where we could not gain any type of access.

The man's four friends were so determined to have this paralyzed man meet Jesus they carried him up to the roof. They removed the tiles of the roof and through the opening lowered, as Mark says, " the sick man on his stretcher in front of Jesus. "

We all know the bright and happy ending of this story. We know that the paralyzed man " jumped up, took a stretcher, pushed his way through the stunned onlookers. " We also know how they were changed. Then they praised God, saying, " We've never seen anything like this before. "

There are a forgotten, powerful four people in this story, without whose assistance the paralyzed man would never have been healed by Jesus. Mark states that when Jesus saw how strongly they believed, he decided to help and said to the paralytic, " Son, your sins are forgiven. " These were his words, and the rest is history.

How vital were those assistants, the man's friends and helpers. They were the forerunners, friends of those persons with disabilities, to help miracles to happen even in our own day. How strong is our belief that access is possible when it seems impossible That it may be through the roof, as in the time of Jesus and must always be through the heart, as it was in the minds and the hearts of the stretcher bearers.

Rev. Donald Senior, a current Passionist Theologian from the Catholic Theological Union in Chicago, Illinois, speaks in terms " of those who stand for the defenseless. " Surely, the four friends of the paralytic man definitely fall into this category. We must remember, however, the interdependence that exists between the four helpers, the paralytic man, and Jesus. I wonder what the dynamic was after the paralytic man " jumped up " in the days and the months that followed upon this incident. I wonder who really helped whom.

This question is very relevant to each one of us here today. How deep is our belief in your belief to be ministered to and to be a minister?

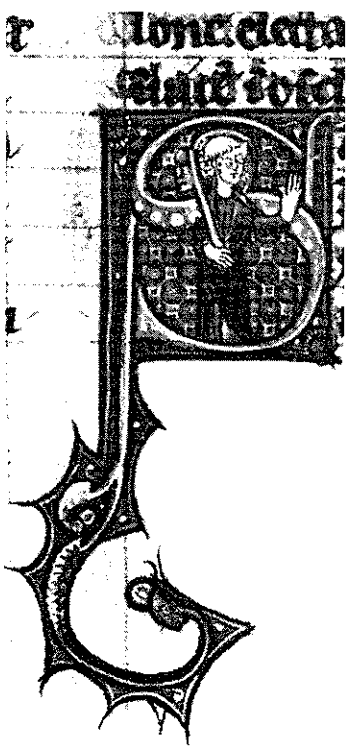
How often have your roles changed from one to another? What is your present role? Is it single? Or is it a dual role?

Let us now examine the affirmation segment of this presentation. Surely one can easily find the historical linkage of disability and illness to sin in the Old Testament of our Bible. Leviticus (Chapter 14) makes it very clear that the priest must offer " a sin offering " to cleanse one from his leprosy. Even the flight of the woman seeking assistance from Jesus after twelve years of bleeding shows that she was in " a state of ceremonial defilement " (Lv 15:19). The reversal of the traditional belief in sin and the ostracizing of the " outsiders " took place in a radical way when Jesus showed us by example what it meant to break boundaries and offend those who were on the other side.

How frightening his confrontation with the man possessed of a demon in Mark's Gospel (Mk 5:1-20). This man, who lived among the gravestones, was so strong that no one could control him. He wandered among the tombs and the wild hills, screaming and cutting himself with sharp pieces of stone. Again, we all remember the story of how Jesus screamed at the demons

who called themselves " legion, " then bargained with them, and finally sent them into a horde of pigs that immediately was hurled off the cliff and into the lake below and drowned. Rarely, however, do we think of the man who was rid of the demons. More rarely do we ask the question about the nature of the special ministry of the recipient of a miracle.

Let us return to the scriptures. The herdsmen fled to the nearby town and into the countryside, spreading the news as they ran. People rushed out to see for themselves. A large crowd soon gathered where Jesus was. As they saw the man sitting there fully clothed and perfectly sane, they became frightened. How totally human is this reaction. The quiet, totally manageable former wild man, the previously uncontrollable breaker of chains, frightened everyone now because he was calm, quiet, and normal. Later, when he asked Jesus to accompany him, he received his orders. Orders as it were, from THE TOP. " Go home to your friends and tell them what wonderful things God has done for you and how merciful he has been. " Mark tells us that he went and visited the ten towns, better known as Decapolis, and that he told everyone about the miraculous things Jesus had done for him. What was their response to this wild man, now turned teacher. Mark states, " They were all awestruck by his story. " Rarely do we hear about this appointed disciple to the gentiles who continued his ministry after being one of the most totally outcast of people.



Jesus spent his ministry crossing over to the other side, walking among the outcast, healing everyone, including the gentiles.

As a boundary breaker, he has set a concrete example for all of us to emulate.

The culmination of his message is the mystery of the cross, our Christian central symbol and sign. Bewilderment is the most eloquent revelation of God. Jesus' wounds remained even after his resurrection from the dead. His disabilities were the great sign of our salvation.

Let us look at our mandate to affirm and to change. Let us follow the lead of the four helpers of the paralyzed man and also the exorcised madman of the Gadarene. Let us follow the crucified Christ as a boundary breaker in this our 20th century.

Let all the world come, see, and feel our salt on boundaries that are arbitrary and dehumanizing. Let them rightfully be filled with awe at the wonderful things that God has done for them.

When we speak of affirmation, we are indicating that what we refer to is true. It is based on a knowledge of the situation that is affirmed. It is an explanation of the value of change. Affirmation is a declaration of both charity and justice. Today what we propose to you in a biblical context is that not only are the winds of change blowing in favor of persons with disabilities, but that it is a gentle but continuing storm that is creating new visions, as well as indications that it is to be an ongoing reality in our world.

Change demands release from the past, releasing attitudes and concepts that for too long a period of time have described the population of persons with disabilities erroneously. The growth of change has been slow because it demands the personal burial of prejudices, fears, and uncharitableness. However, in our present era it has grown into strong active advocacy. Perhaps most significant is the change from sympathy to acceptance—from ignorance to knowledge—from doing *for* to doing *with*. It is this slow but steady change that is the cornerstone of hope for every disabled person, as well as the members of their families.

It is impossible for us to accomplish this enormous task alone. It is a task that requires community cooperation, dedicated love, and prayerful personal action. Convinced that change and affirmation are possible, we must leave this conference with a well defined plan. Can we do it? The answer is definitely yes. Let me cite the most impressive achievement of human rights, justice, and love for all in society that has occurred in the United States—The Americans With Disabilities Act (known as ADA). Persons united achieved this remarkable, wide, sweeping, all—embracing legislation. By conviction nondisabled people allied to people with disabilities, and disabled persons themselves were convinced that change was demanded and possible. This mutual conviction affirmed that time, sacrifice, and hard work would spell success. Wide, sweeping advocacy of these two groups, disabled and nondisabled persons, as well as many who never had given much thought to the matter but who were the recipients of intense education, enabled a crescendo to grow and to call for change. The call developed into a proposal—the proposal, into a law.

Let us return to that inspiring story in the New Testament known as the Parable of the Good Samaritan. A man was traveling—he was assaulted by robbers, who not only seized his possessions but also physically injured him, leaving him on the road near death. Three persons, traveling separately, were on the same road behind him. The first to see him looked and continued on his way. The second person, coming upon the scene some time later, also looked and continued on his journey. Finally the third person came by and, immediately seeing the man's distress, stopped, assisted him, and took him to an inn. He paid out of his own money for care for the injured man. As he left to continue his business trip, he as-

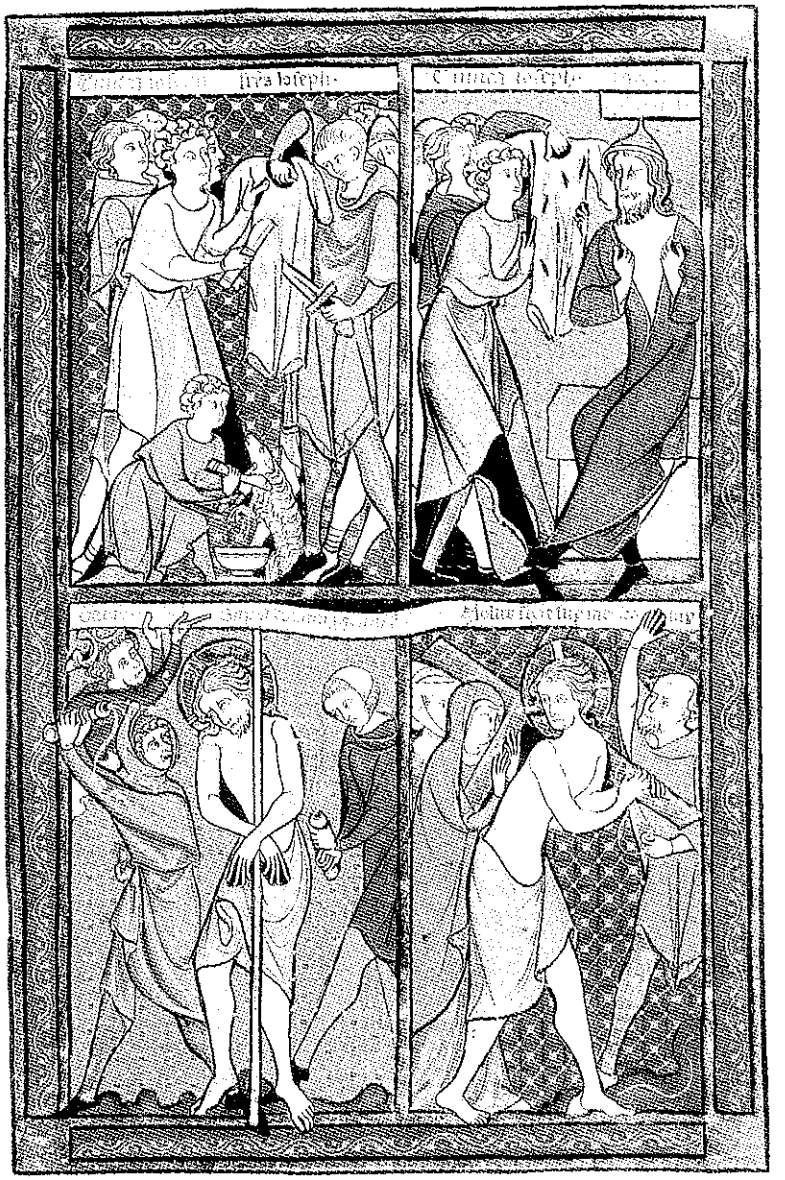
sured the owner of the inn he would pay when he returned if there were additional expenses due to the care the injured man might need

To the listening crowd, Jesus asked a direct question—" Who was a true neighbor to this injured man? " The answer came that it was the third man.

Jesus gave a very simple command: " Go and do in like manner. "

If that injured man lying by the roadside is a symbol of our disabled community, we are the members represented by the third traveler. Let us, therefore, listen carefully to the command, " Go and do in like manner "—be people of compassion, prayer, and action, FOR and WITH *all of our disabled brothers and sisters*. Thank you and God bless you.

Monsignor THOMAS F. CRIBBIN
Chairperson, National Catholic Office for Persons With Disabilities, Washington D.C.



MICHEL GILLIBERT

The Prevention of Handicaps: Duties of the State and Society

First of all, we are all very honored and moved by the fact that His Holiness wanted to welcome us—and there are very many of us—here at the Vatican, and in this place which is so full of history—the history of the relationship between the Infinite and men of Faith.

I would like to stress to His Eminence, Cardinal Angelini, that his immense work, his obstinacy in understanding and loving the human being, today rewards us with this exceptional and high-level congress, which is dedicated to advancing the well-being of the silent world of those casualties of life —handicapped people.

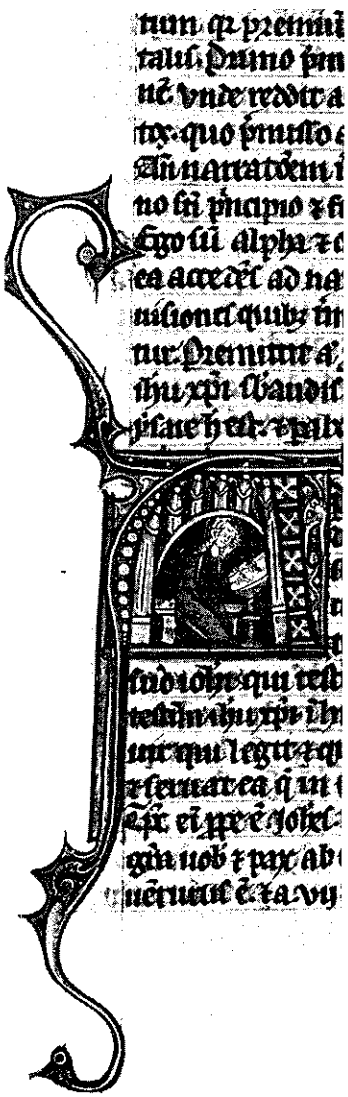
We give you thanks from the bottom of our heart for having offered us this opportunity to meet and try to defeat injustice and pain.

His Holiness wanted to do me the great honor and grant me the privilege of receiving me a few months ago to speak to me about handicapped people, the casualties of life, and about the need to change mental attitudes towards them.

This unique meeting was marked by a simplicity and vital and profound spirituality.

I was able to express my vision to His Holiness concerning the world of the handicapped and to ask for his valuable help in changing mentalities with his words. It is necessary to turn over the page of pity and speak of the present, of the future of the handicapped, with the words of everyday life.

John Paul II immediately gave his assent and offered his support to pass this message through the Catholic Church. This philosophy was born in me after an accident that I had, thanks to a realization of the absurd and the ridiculous which often form a part of our daily lives.



I explained to the Holy Father that a great lucidity of this daily nothing must attract us towards an absolute certainty. This nothing appeared to me in a very practical way when I tried to regret, the day following the accident, the life that I had passed prior to that moment.

I then realized that the first step of displeasure in the drama is in itself a way of approaching things. It comforts a state of the soul in which complaining about one's fate itself seeks to be a consolation.

Indeed, it expresses our hopes about the past projected onto the present and makes us forget that which is fundamental in us: our conscience. That is to say, our responsibilities towards ourselves and towards others, and towards our infinitely small personal world.

It is necessary to get rid of what I call the " diabolical four "—appearance, possession, wanting, and power (if not at the service of other people).

An attempt should be made to acquire a sense of responsibility which then becomes freedom.

What, then, is this definite nothing? A daily habit. It is often admiration of, or being content with, what we think we are, and this because of the superficiality of those terrible " four " that govern many selfish lives. It is a matter of not having any sense of the true measure of things.

It means giving oneself over to the absurd idea that one has marked time. It is, finally, to get what is essential wrong.

When faced with the infinite, how can we not reflect upon the smallness of what we are. Humility is a source of unparalleled richness.

How can we accept the material without being profoundly struck by that which represents its beginning and its end without giving a profound sense of what comes afterwards? How can we accept the difference of our presences?

For example, one person upright, the other person broken in his chair. At first sight the first has everything, the other has nothing. But where there is everything, there can be nothing, and where there is nothing, there can be everything.

A word which was not invented by men is love. It is part of the intangible, it is a part of the impalpable which is given and is received. Love is the fundamental energy of the infinite, of the inexplicable which contradicts the solitude of that which is material.

God is not the master of nothing. This nothing of daily life, this comfort to selfishness, of a pleasure without creative imagination.

A nothing defined and organized by men so as to be able to possess and manipulate other people more effectively. We cannot make God responsible for this daily nothing.

When the accident happened, I became another person in the space of a second. I should, therefore, have met myself and known myself differently.

The " less " became the " more... " What seemed to me to be most important was that I had to relativize these words in order to live the truth at a deep level. In this way, " broken " for ever, I would have ended up " standing. "

At that point I decided to create for myself a universe of solitude in order to examine what at that time seemed to be confused: the essential. Alone, completely alone, that is what that moment wanted me to be.

I wanted to reflect upon my past. In a strange way, in assessing its real importance as I had lived it, it seemed to me to be too superficial, too ridiculous for it to be wanted by me anew.

The importance of things is bound up with the game we are playing. When that stops, everything comes to be questioned.

The splendor of what I had experienced fell apart as I reflected day by day—it was too selfish.

I no longer had the wish to live like that because the silence of my soul as it waited involved a wish for something else. In this situation it imposed itself on an emptiness decided upon and defined by men.

A new birth was taking place. I was going to discover it detail by detail as I came into contact with other things in a different way —with a sense of spiritual values.

Difference is a unique richness which belongs to nobody but GOD. It has the right to be born, to live with dignity, justice, and love, in all that which goes to make it up.

When a being ventures to judge it, such an aspiration goes against the spirit of the Gospel and against the mystery of the infinite.

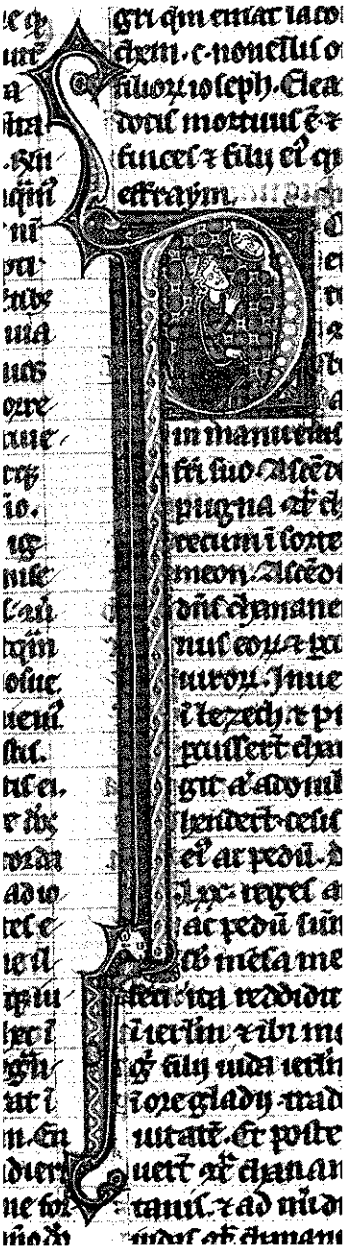
Those who have been cruelly struck by the ill-luck of life should try to close the door on their past without regrets. But, as a result of their internal strength, acquired through their own experience, they will fully live out their rebirth with other people.

The needs of handicapped people, those afflicted by ill-fortune in life, consist in presenting a new face to the eyes of those who look at them, who speak about them, often with an element of contempt and questionable kindness.

The quality of a human person is not connected to his external appearance but to his internal richness. People with motor, sensory, or mental handicaps—whatever category we belong to, we have something to give and to receive in our relationship with other people, because each one of us is a human person. Love, affection—these are vital needs. For those who suffer, perhaps they are such to an even greater degree. This beauty of the soul we carry every day, and at every moment.

Notwithstanding political developments and the socioeconomic advances of our systems, handicapped people—those who are casualties of life—have remained for centuries on the lower rungs of the scale of priorities of our responsibilities.

Society has often preferred to hide and to park this part of the population in buildings, or forget about them. It was a way of getting



rid of us, of canceling us out, and of marginalizing us

The organization of daily life was reduced to a kind of survival, and often only for those who had the wherewithal—eating and sleeping, accompanied by certain kinds of treatment given with great dedication but without attempts at development and without hope of an existence with the same rights and choices offered to every man and woman at all times.

The general opinion was that these people could not do anything that other people did. For heaven's sake! It was feared that they would get tired or that they would injure themselves. Integration was a word drained of all content and connected to what was inconvenient, so strong and disproportionate did it appear.

Then the associations sprang up. Their daily work and the will of the handicapped acted to push back indifference. It was a titanic endeavor because the spirit is heavy when one is dealing with an effort to help other people

Today, it is beginning to be understood that people who are handicapped have the right to benefit from an overall policy which takes account of all the moments of existence The objective that we must aim at is the independence of these casualties of life in line with the full potential of each one of them.

All of us who are present here today fully recognize that every woman and every man must have the opportunity, each day, to choose their own form of participation in the active life of our countries.

We must break down all those barriers which stop these people from having access to their share of happiness.

The handicapped person must not be the object of protective and subsidizing policies. He must be taken into consideration, within a framework of integration and the achievement of full citizenship.

Because of the fact that a handicapped person lives like everybody else twenty-four hours a day—although in a different way, an overall policy towards handicap should be created and the needs of these people should be integrated into the basic framework of all plans and programs. This will be useful to everybody!

The overall policy towards handicap is a chain of life where every response forms a ring. We cannot be satisfied by seeing this or that particular aspect improved if more general problems are not solved.

Piecemeal and impromptu policies are onerous and mere flashes in the pan because the improvements which they achieve with precision often turn out to be ineffective, for the problems with which they are connected are not solved.

In this way, for example, the involvement of handicapped people will remain an inaccessible island until we have settled these questions of training, transport, access, accompanying, the adaptation of workplaces, and so forth.

This is the philosophy of our action in France and in an ever-increasing number of countries. In line with this philosophy, it does not seem to me to be a good idea to outline specific rights for handicapped people.

I would go even further—the demand for specific rights for handicapped people goes against a true policy of integration of these people. When we seek to do the opposite, we marginalize them even more, and I know that the majority of you here today share this point of view.

On the contrary, it is the responsibility of governments to provide handicapped people with the instruments by which to exercise their citizenship fully, in all its fields, whether social, economic, political, or cultural. This should be done taking full account of the different kinds of handicap—physical, sensory, and mental—and of the needs of the person who, it should be understood, can develop.

In France the Secretariat of State, entrusted with the portfolio of handicapped people and casualties of life, has worked for over four years to provide these people with the chance to live with dignity and to have full access to citizenship.

Such a cross-ministerial governmental structure, which was set up by the President of the Republic, allows this policy to be followed and fully involves the government, members of Parliament, and the

men in the field in the mechanisms of integration.

I wanted this definition, " casualty of life, " to replace the term " handicapped. " This latter term has come to acquire an overly pejorative connotation.

The term " handicapped " marginalizes. The term " casualty of life " refers to all those people who are different from birth or because of illness or an accident. It is a phrase which uplifts. An accident is an event which does not prejudice the future. Life is a word of hope

Discovering the Handicapped Person

The first ring may be called information For example, how can the parents be told in a positive fashion about the birth of a different child? This moment is fundamental. It can bring energy and hope or disorientate, discourage, and even lead to desperation The information must be general, must gradually render the entire population more active, aware, and concerned about all aspects of handicap.

This is especially true with regard to the parents. The child, right from birth, can gain much from preventive measures which diminish the handicap when there are precise diagnoses which allow an individual assessment of the nature and level of the deficiency involved It is necessary to provide information on therapeutic approaches and techniques which are themselves in a state of constant evolution.

This prevention must be permanent so as to avoid an aggravation of the situation, complications, and any associated difficulties that might arise.

The training of the medical and paramedical professions must be more precise in order to lighten the character and impact of disability

Too often general practitioners are not sufficiently aware of how many difficulties and vasomotor reactions handicapped people have to undergo every day of their lives, even though solutions exist.

The training of medical and paramedical personnel in this area would enable us to eliminate daily suffering and difficulties which are of little help to handicapped people and expensive for our respective countries.

We could, for example, begin with the provision of information to the obvious sections of the population through the use of audiovisual methods. In this way simple treatments could be taught which, notwithstanding the new instruments that we have available and new knowledge that has come to us, are not always attempted. In the same way, it would be a good idea to make all professional workers in this area more aware and concerned with the whole reality of disability.

Giving Priority to the Education and the Training of Young Handicapped People

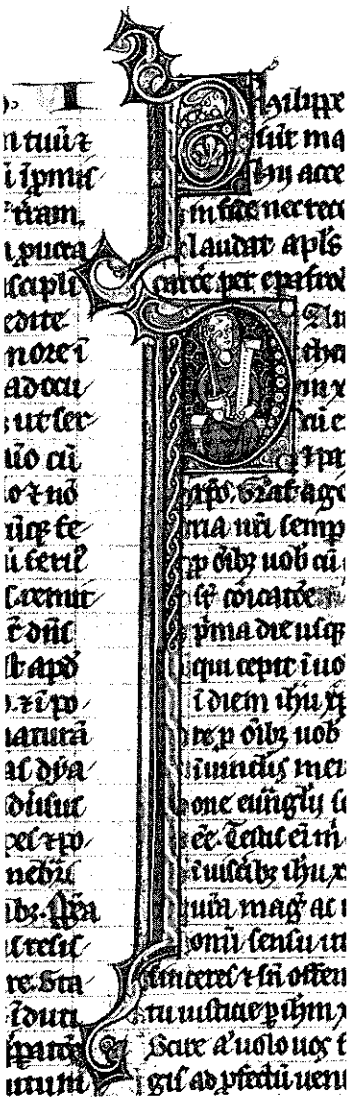
Social integration must begin in infancy. At school, handicapped children are too often still the victims of manifestations of exclusion. School, however, should be open to everyone

How can we talk about integration if handicapped children do not have the same opportunities as the other children? Education forms the basis of a future made up of independence, choice, and integration.

We have to struggle constantly to make sure that children who are different benefit from the education that is provided to everybody in a shared environment. Educational action also takes place in a family context. For this reason, in France the new guidelines involve parents in the educational project and, at the same time, encourage specialized institutions to extend their activities into the common environment.

School integration can take different forms—individual integration and collective integration—but whatever form it takes, it must be well planned. It is necessary to avoid these children feeling rejected from the early days of their lives. This requirement can be satisfied, in particular, through training of the teaching staff.

In the universities we must try to find shared solutions to the needs of all the students through a use of



new technology and computer science.

Increased awareness and political will must favor an overall consideration by both handicapped and nonhandicapped students of the question so that new initiatives can be taken which will be of use to the whole student body.

It is the students themselves, especially when a suitable occasion arises, who must find answers, and they must do this in conjunction with the teaching staff and through the university structures.

Gaining Access to Jobs

The involvement of handicapped people in the work process—that is to say, their training, the professional re-education of handicapped workers, and their introduction into the conventional or protected work environment—involves the most natural form of participation and means that they act in common with other people, meet them, and live and exist with them.

It is a specially advantageous means of achieving integration which respects the dignity of men and women and enables them to avoid feeling useless to themselves and to other people in society.

The first obstacle is often psychological.

For their part the heads of businesses must be aware of the fact that it is in their interest to have handicapped workers amongst the people that they employ. They must consider the handicapped worker not in relation to his handicap but with reference to what he can actually do.

Emphasis should be put on information so that the heads of businesses know what handicapped people can do with all the different characteristics that they have.

They are very many well-documented cases to show that handicapped workers are less work shy and actually work better than nonhandicapped staff.

New kinds of technology and in particular the world of computers are revolutionary means by which to ensure that those afflicted by more serious forms of disability find a place to occupy in the world of work.

We should also make it known that the mentally handicapped have their place in active life and very many positive experiences bear out the truth of this observation.

In some European countries, laws require businesses with an average of more than twenty workers to employ a certain proportion of handicapped people. In France, the law fixes the quota at 6%.

We must also be careful not to penalize handicapped workers by reducing the financial help they receive when they manage to find a job. We should, indeed, take into account the increase in costs caused by the disability.

Finally, a position of work will remain an unobtainable island for handicapped people if the problems of accommodation, being accompanied, and access and transport to the workplace are not solved

The Development of Access

Accommodation

Handicapped people must have suitable places to live which take the diversity of the disabled person into account. These homes must be situated amongst other homes to allow natural meetings and the spontaneous discovery of differences and mutual richness. In this way, each person will find his own place in the collective life of blocks, districts, and cities.

The question of access should be considered in its entirety. I am referring here to access to public places, schools, places of work; to the arts and to culture; and, finally, to simple, everyday places.

The street is the place where all social sectors have the same rights.

Transport

Transport, it should be clearly understood, must be accessible to everybody.

How can we accept the fact that a person is forced to remain isolated, shut up in his home or in a building, with the excuse that he is different, while, at the same time, society fails to propose any alternative?

For years different means of transport have been studied which enable people to meet each other. But handicapped people have not been given the right to benefit from these new advances in transport.

How can we talk of integration or independence if a " different " person cannot move from one place to another like everybody else?

Difficult in moving about can do nothing but aggravate the disability, the solitude, and the exclusion that handicapped people have to suffer. It further reduces equality of opportunity in everyday life.

Today we can see the success of certain forms of transport which are accessible to handicapped people and which work to the advantage of everybody. Unfortunately, however, forms of public transport designed for the population as a whole are still not sufficiently adapted to the requirements of disabled people. A tenth of the population is handicapped or casualties of life. A tenth of the population is " condemned in advance " and wrongfully deprived of freedom.

This fact provokes neither scandal nor reaction of any kind. How can a disabled person find a job and even want to work when the simple fact of going forth into this hostile world constitutes a great effort?

What should happen is that in every country the architectural schools should so train their students that from the beginning, and in systematic fashion, the whole question of access is taken into account. This is what we have decided here in France.

Being Accompanied

All these plans and ideas are meaningful only if a third person is involved to accompany the disabled person. This third person does those things that could never be done and can no longer be done.

From 1981 onwards, a new initiative has been in operation in France which allows a certain number of young people called upon to do military service to dedicate themselves to accompanying the disabled This takes place after a period of training.

Naturally enough, other means exist in this realm such as the development of a " co-helper " for

life. It is important that each person, using his own methods and systems, makes an effort in this direction in order to render the life of the handicapped person easier and more livable.

Upholding the Right to Entertainment, Sport, and Culture

The integration of handicapped people is also achieved though their participation in the structures of entertainment and those which allow them to engage in sports.

For this reason, practical measures must be taken so that handicapped athletes can benefit from a system which allows them to train, take part in championships, and receive the same rewards as other athletes. The present-day situation too often involves marginalization.

Sports facilities should be open to everybody and should involve arrangements which take full account of the differences which may exist.

Artistic and cultural development represents a priority in this field because it allows handicapped people, whoever they may be, to be on the same level as other people without being immediately penalized from the start.

The chance to develop creativity and imagination must be given to people who cannot communicate with other people or who are rejected, once again, far too often and in systematic fashion, by preconceptions.

Art is a school, a philosophy. It is not racist in the eyes of the Creator.

In the protected buildings there should be special moments guided by painting, sculpture, and music teachers so that handicapped people, casualties of life, can discover these means of communication, appreciate them, and, subsequently, choose to go ahead in this field in particular.

Handicapped artists, and in particular the mentally handicapped, allow us to discover a surprising world which is rich in imagination and sensitivity. It is something which enables the disabled to have another form of communication with other people.

This is another source of unknown richness which should be developed.

We must increase the exhibitions and the number of shows that are held in order to change people's mentalities and give legitimacy to all these artists.

Breaking Down Isolation

A person with a motor handicap, a deaf person, a blind person, or a mentally handicapped person—all these people, and many others, are marginalized and systematically thrown into solitude by that real problem which our society thinks it knows well—namely, communication.

We must make an extremely important effort in this field to free these women, men, and children from indifference so that they bring their richness to everyone and gain from the constant evolution of our societies in both human and technological terms.

We handicapped people want to choose the greatest independence possible. And we can do it thanks to the will and the solidarity of everybody.

On the other hand, information on all the aspects of disability and handicap must reach the whole population through radio, television, the press, and works of cinema and literature. Handicapped people must speak, in the same way as other members of the population, on all those subjects which concern our societies.

We should not be content with merely producing programs specifically on handicap which only risk a consolidation and strengthening of marginalization and are of little interest either to handicapped people themselves or to other members of society.

The casualties of life must be invited to speak about their interests, their future, and their wishes —not about the problems connected with their handicap.

Old Age and the Handicapped

This reality must take place in a calm fashion. Very often, however, the difficulties that are met with do not find good answers. We must look together for ways of offering these people, who have already suffered a great deal in their lives, ways of finishing their lives in the most dignified and sweetest ways possible.

Hon. MICHEL GILLIBERT
Secretary of State for the Handicapped and the Casualties of Life, Paris

FRANÇOIS RÜEGG

A Problem Often Hidden: The Handicapped Child

Concentration camps for " irremediable " children were discovered in Romania two years ago. This fact shocked public opinion. What was it that had led to a rejection of human beings whose only fault was to have been born? Other concentration camps have since been found and these, too, were found to have hidden children.

When I was a little boy one still saw people who were called " abnormal " in the country districts and villages. There was the village idiot, the lame person, the mongoloid, and the person with a goiter. Each of these people had a role within the community.

I have cited these two examples in order to approach the question of disability from an essentially cultural point of view. It is my intention to employ this point of view in my paper today. Nowadays we all recognize the importance of cultural factors in matters relating to social and even economic action and policy. Unfortunately, this recognition has come very late in the day and after many mistakes have been made—errors which have caused a great deal of suffering. In very many disciplines which at one time were covered by medicine alone, other forms of study have been introduced in order to give a wider picture—psychology, anthropology, and in a general sense all the human sciences. What is now taken ever more into consideration is not only the sick person or the illness but the context within which the sick person or the illness exist. The very concept of health has gone beyond the narrow psychic or physical field, and it now seems that we are beginning to admit that being healthy can mean " having the strength to live with handicaps. " We are very far from the eugenic criteria towards which certain forms of scientific advance direct our attention and interest.

The dialogue that a society holds on the subject of handicapped people, and in particular the disabled child, is rarely explicit. It is necessary to dig deep and to explore vocabulary, attitudes, habits and customs, and their justifications. The disciplines of history and social psychology have revealed this dialogue (and its practical expressions) to us through a study of the family, death, illness, and madness as they have evolved over the ages.[1] Unfortunately, the social sciences are often ignored by those who work and are active in the social field, namely the experts—from the doctor to the social worker, whether voluntary or an international official, in short those who have decision-making powers. It seems to me, therefore, useful to draw attention to three aspects of this still eminently hidden question. My aim is to illuminate some of the obstacles which must be overcome by those who seek to serve disabled children, and thereby aims to help these people avoid falling into the trap of being, so to speak, mere givers of lessons.

1. The problem of the disabled child is a hidden problem because it is something which is not *spoken* about or which is spoken about in an overly simplistic fashion. Here one is operating at the level of dialogue.

2. It sometimes happens that the disabled child can be *physically hidden*. He can be excluded, put in a hidden institute, like those which were discovered in Eastern Europe, or confined to his home for reasons which can be both cultural and socioeconomic. Here one is operating at the practical level.

3. The problem, finally, is hidden in the context of treatment when the doctor concerned devotes himself to the symptoms alone. The child is considered first and foremost as "disabled." He is not thought of as a "child" who is part of a community or a family. Here one is operating at the personal and contextual level.

1. A Revealing Dialogue

A Dark Past?

Notwithstanding the examples which spring to mind of recent natural integration of disabled people—such as those cited by me in the introduction to this paper—the past is nearly always seen as a dark period, as less "advanced," as more primitive than the present. Is it, perhaps, a case of our being conditioned by recent technological changes which cast a shadow over the most distant past? But the evolution of medicine and plastic surgery tells us very little about the transformation in attitudes towards disabled people. Indeed, numerous studies[2] have shown that forms of behavior towards the disabled, and most especially towards children, do not follow a progressive trajectory over time. In Europe, certain communities have looked after disabled people in integrating fashion ever since the fifth century AD. In other epochs their destiny was one of rejection and discrimination. Full mention should be made of the tradition within the Church of helping and integrating disabled people, most especially in the monasteries. The same may be said of the experience of non-European cultures. Rehabilitation services have been found to be active in Asia roundabout 2,500 BC.[3] This does not mean that the list of attitudes which lead to abandonment and a lack of care has not been longer and more influential than their opposites down the centuries.

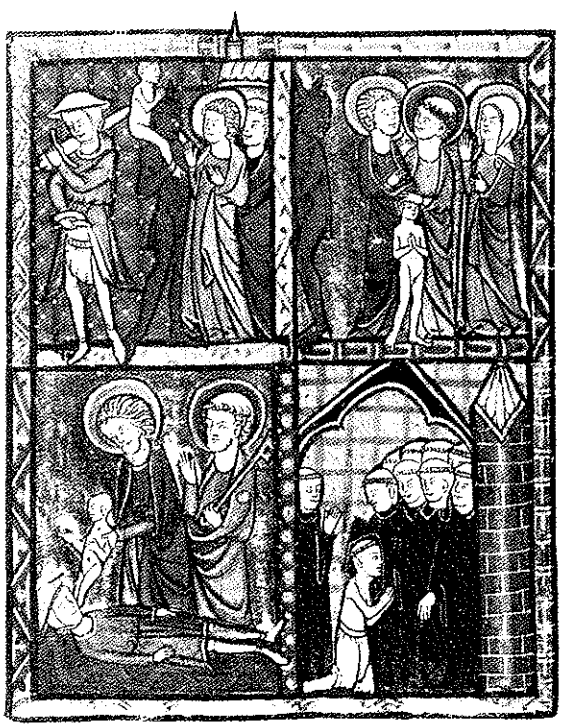
Because we have a poor knowledge of social history and the customs and habits of non-European societies, and because we are still immersed in the concepts of evolutionism, we still have the global image of an ancient society in which the disabled person is not only considered a malediction but is also ill-treated, and in which children afflicted by malformation are systematically destroyed (Oedipal exposure).

Primitive, Savage, or Supernatural?

It is obvious that each society interprets the strange and the unusual in the light of its own cultural (and religious) schemata. But these interpretations (dialogues) do not necessarily give rise to negative attitudes. One need only call to mind the role of blind people in ancient times, or of disabled people as intermediaries between heaven and men, or simply, and more recently, as I have already observed, the role performed by the "village idiot," the lame messenger, or of many other similar figures.

Just as early ethnology created the category of "primitive" peoples, so have we projected onto what we have learnt to call the Third World concepts,customs, and habits which are "savage." The idea, of course, is to eliminate them in the same way as we have rejected our far-off and shrouded past. We are dealing here with what many authorities call "superstitions"—the term is sufficiently pejorative to give the idea that such practices should be got rid of. Many phenomena come under this heading—the supernatural explanations of handicap, the evil-eye, curses, witchcraft. This is not the place to show that our societies, hiding behind and through rational appearances, function in a similar way—something that has recently been demonstrated by the AIDS epidemic.

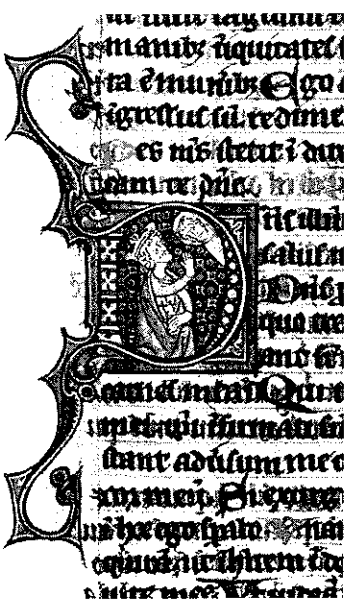
From this analysis, obviously enough, we must exclude disabled children whose disability has been caused by war or by car accidents.



This is because these causes have appeared only in recent times and as a result of, and in line with, inventions which, if we followed a certain logic, we could indeed call " diabolical "!

The Right to Be Normal

In my opinion one should remember not so much the reasons invoked to " justify " a handicap as the need to justify it in discussion Destiny—with all its different expressions ranging from the evil-eye to pure bad luck—is something which is disappearing from our technological societies The rejection of the notion of destiny thus provokes, in societies such as these, a strong emphasis and reverence for the concept of normality, thought of as a right. This explains the evolution of the vocabulary used over recent years to describe disability. It also explains the development of treatment and the removal of social barriers. If, on the one hand, this way of looking at things allows an integration of the disabled child pushed to extremes, it can also end up with a defence of eugenics, or, at the very least, lead to the creation of a host of frustrations on the part of children who will not be benefitted, chiefly for economic reasons.



It is my opinion that it is dangerous to deduce that one discourse is better or worse than another. We would risk penalizing these children even further by undervaluing the culture to which they belong in an attempt to help them Street children, to give just one example, have already been subjected to this " devaluation " The mass media have a very dangerous responsibility in this area.

It should be emphasized that we must distinguish between the dialogue and the attitude or practice which accompanies it In this way we avoid arguing that a " fatalistic " explanation of the handicap implies rejection or abandonment in the same way that a scientific dialogue does not mean that the person of the child and his environment will not be taken into consideration.

2. The Hidden Subject: The Child

Many projects and programs aimed at helping disabled children make reference to the fact that these children often remain hidden because of the shame felt by the family and that the family regards this reality as a malediction At times they fear a physical or moral contagion. However, opinion differs upon the frequency, and sometimes the existence itself, of this practice.[4] Whatever the situation, we must ask ourselves if the causality of these practices is to be found only in beliefs and customs and whether such things belong to the Third World alone.

Experts agree in stressing the importance of socioeconomic factors in producing the phenomenon of " imprisonment " and shutting the child up within the family home. What often leads the family to hide the child is an economic situation which is precarious, the presence of other dependent children, the absence of resources, not to speak of family situations where there is only one parent or where the family involves previously married people. In these cases one cannot conclude that there is a belief in a malediction or some similar form of irrational behavior which leads the family to hide the child. On the other hand, the presence of a handicapped child can be considered a malediction in certain economic and family situations. In certain cases the imprisonment can be linked to an excess of attention paid to the child, to an excess of protection directed towards the child. Because the child lacks a social life, he develops a subsidiary handicap. Werner cites the extreme example, which occurred in Latin America, of a little girl brought into a clinic by her mother with a box over her head with two holes for her eyes—the box existed to conceal a hare-lip.[5]

We cannot discuss this question without discussing the subject of *institutionalization*. In certain cases, this phenomenon can clearly be a way of hiding the child away. The debate is certainly not new, but the discovery of institutions for " irremediable " children in Romania has left a deep mark on the way in which disability is viewed. Unfortunately, it seems that these prison-like institutions are to be found in many countries. Notwithstanding the fact that not all of the children consigned to these institutions were handicapped, they became so, which is something even more serious. Is it perhaps necessary to remember that abandoned children, as well as physically and psychically handicapped children, were thrown together into these morgues? Here we are encountering political violence, as well as both moral and material poverty. Indeed, terror and ignorance have led even the staff in charge of care to participate in this conspiracy of silence—a silence on the outside about what really happens to these children and a silence towards the children themselves, to whom is denied human contact, words, even a name.

Utilitarianism and ideologies based upon race or purity of natural selection are fully evident in this monstrousness, and this shows, once again, how the hidden child is not a product of the Third World but a product of wickedness, if not, indeed, in the first case, of perversion. Or, as in the case of families below the level of survival, whatever their geographical location

might be, the product of powerlessness and of human incapacities.[6]

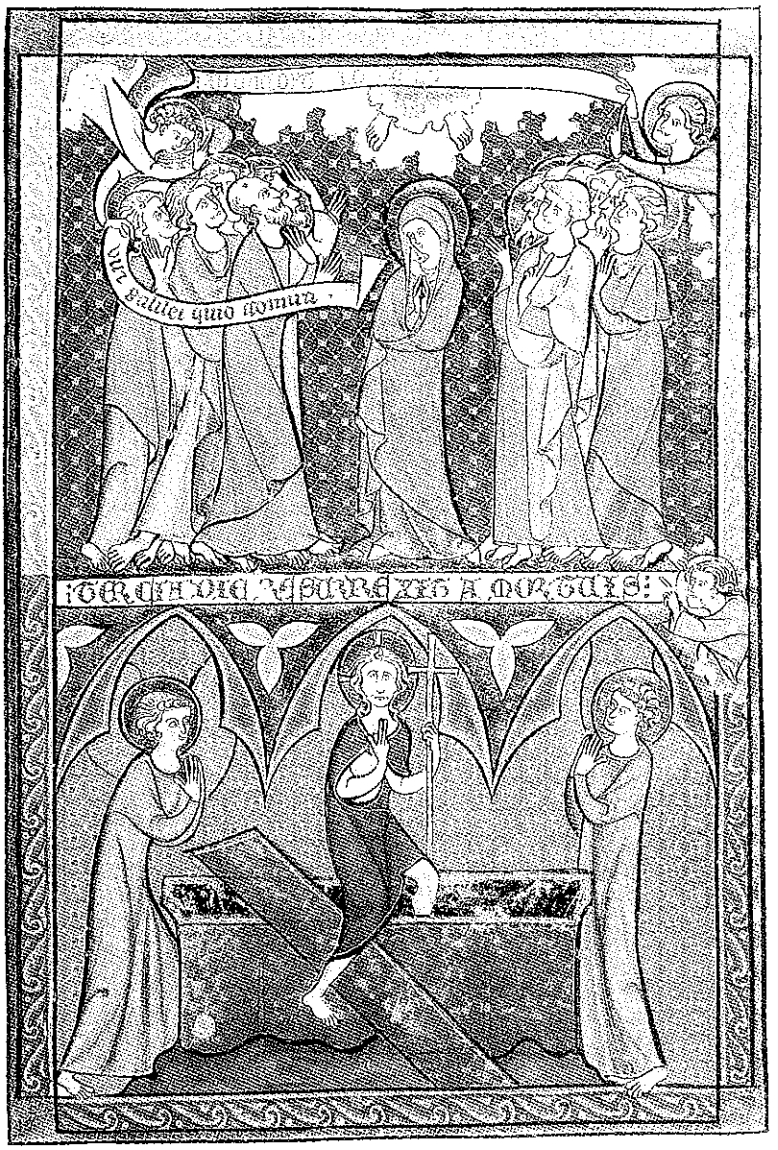
3. The Hidden Person: Medical Imprisonment

Medical specialization has undoubtedly involved a multiplicity of advances in the treatment and cure of ailments, and the prevention of handicap comes within the compass of this development. But it is also true that this very specialization has also involved a kind of segregation —instead of treating the child the handicap itself has been the object of attention. It is interesting to read the account of Dr Goman. He gradually discovered, during the course of his work with other colleagues of various medical disciplines, that the disabled child, also, must have the opportunity to go through the stages of development of the normal child—to pass, for example, through crawling so as to learn how to walk.[7] This allowed him to discover the importance of contact with the ground. Hitherto disabled children in hospital had been kept in bed. Unfortunately, most of the children that I saw in institutions in Romania had never touched the ground and had never seen the sky. On the other hand, in the so-called " primitive " countries, disabled children, or at least those that are not isolated, have access to all the resources that nature offers.

Is it not, therefore, evident, that those who work in the social field and display solidarity in their daily lives should also do so in relation to the disabled child? Neither the family nor the institution are useless or indispensable to the disabled child—their effectiveness is merely complementary. As has been well shown by clinical examples,[8] nothing and nobody can take the place of the family. But an institution " on a human scale " offers very valuable services. It also allows the family to perform a role which, without its support, would undoubtedly become impossible.

The Dignity of the Child

Notable steps forward in rehabilitation have been made, especially by local communities which are able to support the family. But



perhaps the most important discovery—or re-discovery—is to have given the disabled child back his dignity and to have given the community back its function. The recent conference on the rights of children drew attention to the principle of the " best interests " of the child. It also laid emphasis on the role of the family, the basic social cell of society. The fragmentation of values and the loss of " supernatural " or religious reference points makes the importance of this conference even greater.

To draw attention to, and to condemn, the hidden child, means to risk aggravating his marginalization and his frustrations. To make his family, his community, and those who take care of him accept his dignity as a human being and his value is to perform a work of love.

Dr FRANÇOIS RÜEGG
Secretary of the International Catholic Children's Bureau
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[1] ARIES, *Foucault*, ecc.
[2] MILES, *Attitudes*.
[3] MILES, *op. cit.*, p. 3
[4] INGSTAD B., " The myth of the hidden disabled... "
[5] WERNER.
[6] MILES, *op. cit.*
[7] GOMAN.
[8] INGSTAD

WANDA POLTAWSKA

The Handicapped Child in the Family and in Society

1. Introductory Remarks

The general concept of a " handicapped child " comprises a number of quite different life situations. There exist different sorts of innate and acquired disabilities and not all of them make a person quite helpless. Moreover, there appear in different countries and at different times different diseases, so that an analysis of the situation of a disabled person must take into account the social and cultural circumstances in which the person lives. The scope of my experience in the field of juvenile psychiatry comprises persons with different grades of mental deficiency from the gravest cases to a light degradation of mental efficiency (e.g. *fatuitas mentalis*). Although my experiences are confined to the area of Poland, I think that some of the conclusions to which I came when dealing with those cases may be regarded as general, because the reactions of people are, in general, similar, in spite of the differences in their milieu; in particular, the reactions of a mother who suffers because of her child's disease seem to be the same in the whole world. A mental handicap may be connected with a disability of another kind, and deeper disturbances are usually connected with other developmental defects; thus, the concept of a " handicapped child " needs some more precise qualification.

2. Genesis and Etiology of Mental Deficiencies

In spite of many investigations devoted to finding the real causes of mental deficiences, we are not able, in many cases, to ascertain the pathogenesis of those diseases. The attempts to interpret those deficiencies provide more and more information about the harmful factors which have brought them about; among the factors whose influence has been investigated both hereditary and different toxic factors are mentioned. Nowadays, in order to eliminate the harmful factors, one puts more stress on the hygiene of pregnancy; another eliminates some medicines; another speaks about the harmfulness of nicotine and alcohol, etc. Some medical information is even contradictory, and the search after the factor which set back the child's intelectual development continues.

Observations performed in different cultural circles lead to different conclusions. Thus, American medical literature denies that the father's alcoholism leads to mental deficiency of his children; but my investigations in Poland have clearly shown that a statistically significant percentage of fathers of mentally deficient children are habitual drunkards. Thus, my conclusion that the father's alcoholism does influence the mental development of the child is a conclusion *ex post*, from medical practice—although we have no genetic investigations showing any particular changes in the spermatozoa of those fathers.

Neverthless, independently of all possible guesses, we cannot deny that in many cases we are unable to find any harmful factors responsible for the birth of a mentally deficient child in a normal, healthy family, devoid of any hereditary taint; and, on the other hand, we

realize that children of drug addicts, psychopaths, and alcoholics are sometimes quite healthy and very gifted; every child is a surprise, each is unrepeatable, and we cannot predict their fate

3. The Parents' Reaction to the Birth of a Handicapped Child

Before the introduction of prenatal diagnosing, and still in many parts of the world where this diagnosing—diagnosing which enables us to recognize some diseases only—is not practized, the parents are surprised by the birth of a handicapped child. This reaction takes different shapes in different milieus; the reaction of couples who love each other is different from that of those who are surprised not so much by the child's illness as by the very fact of its conception, when the parents are not married or even juvenile; different is the reaction to this fact of mature believers from that of atheists or immature persons.

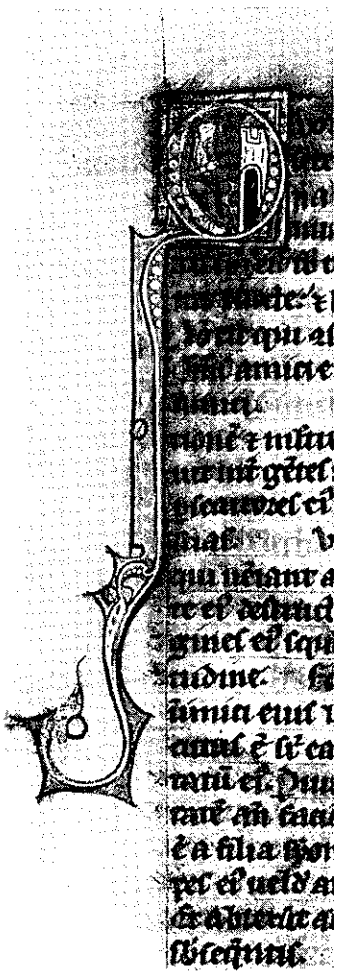
Women and men react differently to the birth of a handicapped child

a) *The Mother's Reaction*

The mother's first reaction to the news that her child is handicapped depends, in the first place, on her situation in life. If she is a lone woman, a girl abandoned by her boyfriend, or is even married, but does not feel safe because her husband falls short of his duties as man and father—she usually rejects the child; she may even not want to look at him, in particular if the child has some visible developmental defects. Sometimes the grandmother takes care of the child, but usually he is sent to an institution caring for the handicapped.

If the defect cannot be immediately recognized and the baby does not look different from healthy children, a child born in marriage is accepted in the family and the child of a lone mother is put up for adoption.

When feeding her baby, a mother becomes more and more attached and may even initially not perceive that the child does not develop normally—in particular, when it is



her first child. When the illness of the child becomes evident, the mother often feels guilty, and this feeling is sometimes supported by the reactions of the people around her who try to make her responsible for the child's defect. Such a pursuit of guilt may lead to a conflict in the couple when they charge each other with the responsibility for the deficiency of the child.

The woman regards the child's illness as an unjust fate, becomes depressed, and sometimes even falls into despair. Believing mothers often initially rebel against God and have a grudge against Him. The feeling of being unjustly wronged and the impossibility to understand the reason for it makes the mother withdraw into herself while her neurotic-depressive reaction grows.

This is always connected with the reaction of fear—fear of the next child, who may also turn up being ill. These women adopt a contraceptive and anti-birth attitude. This irrational fear is sometimes so strong that the woman is resistant to any persuasion and either uses contraception or refuses all sexual intercourse—and this makes the conflict of the couple more severe.

b) *The Father's Reaction*

Some infantile and irresponsibile men do not take any responsibility for their child (It is a very well known fact that the great majority of women who decide to abort are abandoned or neglected by the father of the child.) Thus, a certain number of fathers do not take any interest in the fate of the child—in particular, fathers of children conceived " accidentally, " when the sexual act in which the conception took place is regarded by the man as something incidental and unimportant; some of them even do not know that they have become fathers. If the child is born and the " accidental " father does not deny his fatherhood, his responsibility for the handicapped child is confined to pecuniary obligations and the child is sent to an institution caring for handicapped children. The father has often no contact with his child.

When, on the other hand, the child is born in marriage, the father's attitude toward the defect of

the child is usually better; but he is, as a rule, less engaged in care for the handicapped baby than the mother; later, when the child grows, his efforts are more important. But, during the initial period, he may help the mother very much to overcome the depressive reaction. The psychic balance of the woman-mother depends to a great extent on the man—a loving man gives the woman the feeling of security and accepts her together with the ill baby. But this is not always the case. I know from my practice cases in which the man was able to irrationally accuse his wife of bearing a handicapped child and never accepted the child. Deeply believing persons, who regard the cross as the way to salvation, are able to cope best with this difficult situation, but this is not the reaction of the majority of parents. It seems that the majority of fathers of handicapped children, although they do not have a depressive reaction, withdraw into themselves and a contact with them becomes difficult. They also adopt an attitude of fear of the next child and even, sometimes, wish to adopt a healthy child while fearing to have their own baby. Such an attitude on the part of the parents is a sentence of death for the next child—they categorically do not want to have a second, ill baby.

4. The Development of the Child and His Family

The fate of a handicapped child who has been allowed to live but exhibits more and more distinct symptoms of development disturbances may vary.

a) *The Reaction of Rejection*

A handicapped child, initially accepted in the family, is sometimes, after a while, sent to an institution caring for such children. This is due to different factors, and sometimes seems to be the only possible solution, as such a child needs constant care—day and night—and when both parents work and must, moreover, care for other children, they cannot afford such constant care for the ill child. Sometimes this decisione is motivated by the good of the other children when, e.g., the handicapped child is aggressive and/or restless and his brothers and sisters imitate him. This decisione sometimes makes the feeling of guilt of the mother deeper and makes the restoration of her psychic balance more difficult. It also happens that one of the parents dies and the other is not able to care for the ill child.

b) *The Reaction of Isolation*

The child grows in the family, but the parents' attitude to its presence is traumatic and they are ashamed of having it—in particular, as the people around them are often prejudiced against a handicapped child and the parents feel alone and rejected in their pain; sometimes they try to conceal the child's illness even from their own family. They do not walk with the child and do not invite to their home other children. In the house there constantly reign tension and sorrow—every such situation calls to the society for help, both when the parents endure their fate together and when there is only one lone mother.

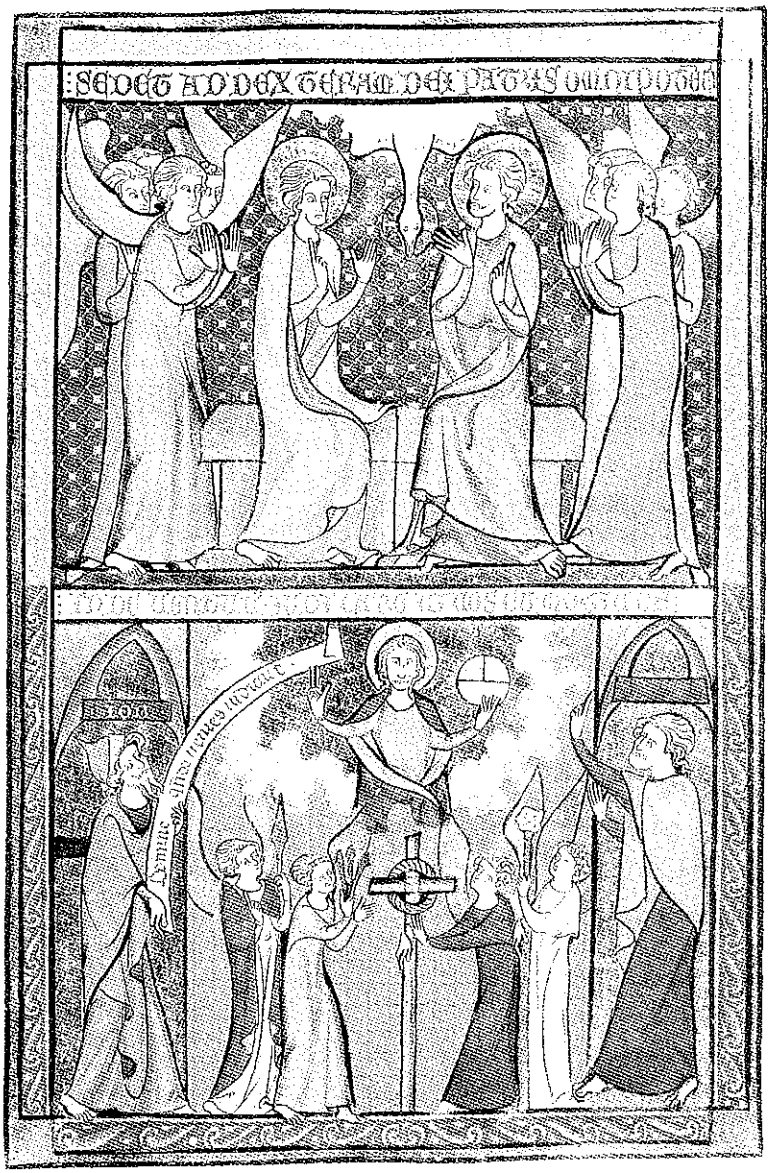
c) *The Reaction of Society*

The fate of the handicapped child lies initially fully in the hands of its mother—not only because she bears it and gives birth to him, above all, because the current legislation of the majority of countries gives the right to the child exclusively to the mother and she alone can decide about its life or death. The present possibility of the recognition of some hereditary diseases, e.g. Down's disease, causes a certain pressure on the mother, who, having learned that the child is ill, hesitates to bear him. Today's world and even the physicians whose proper task is to heal the ill child suggest eliminating him, motivating this suggestion by concern to " defend it from an ill fate " of the sick. A diagnostically established prenatal illness of the baby often leads to abortion. But, when such a diagnosis does not exist or when the mother does not yield to the pressure to kill the baby, it is born. Mental deficiency, when not

connected with other developmental defects, may not be immediately perceived. It may happen that the mother does not become alarmed before realizing that the child does not begin to speak; and, as the ability to speak does not develop with the same rapidity in all babies, it may happen late enough. When the mother or some other person perceives the child's deficiency, there immediately arises the question " Who should take care of the child? "

An ill child is qualified as unfit to be adopted because the adoptive parents seek, as a rule, healthy children; thus, if the case is diagnosed before an adoption, the child will not find adoptive parents. If it is a child of a lone mother, i.e. of a woman who has been abandoned and wronged by the child's father, this task must be undertaken by the state. The system of medical and social care provides a net of homes caring for handicapped children and possibly a system of educational institutions adapted to the possibilities of those children (the age of single mothers in Europe is diminishing every year—the statistics show that more and more teenagers become mothers). A lone young woman, in particular a young girl, is not able to cope by herself with the care of her child, who needs constant attention—day and night; therefore, the child is placed in a home for social care society must pay for it.

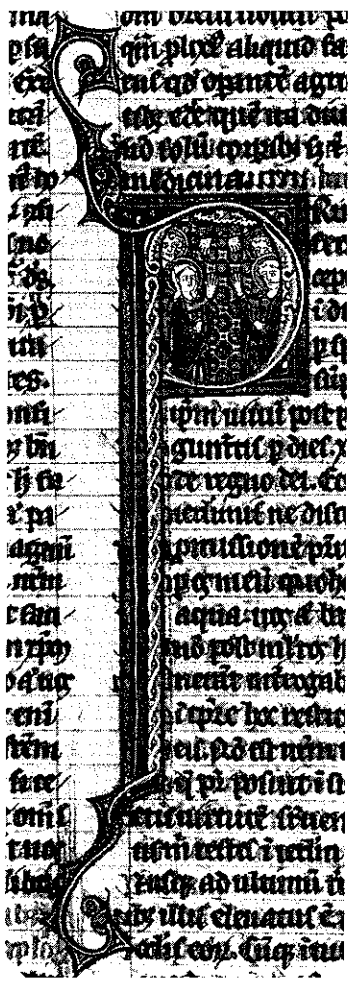
This situation sometimes causes a negative attitude of the society towards those children, observed in different countries. The world does not readily give gratuitous services, in particular as happens in contemporary Europe, which has still not overcome the demoralization of the second world war, when the nazi system simply used to destroy handicapped children. One of the first occurences in Poland occupied by de Nazi troops in this war was the gassing of those children together with the personnel of the social institutions who cared for them. The elimination of the citizens who are a burden for the budget of the state is still a temptation for the politics of the twentieth century. Mothers or parents of those children need help—sometimes the child must be taken from them, and sometimes it is enough to help them



in its upbringing. The attitude of hostility towards the handicapped fosters the mother's feeling of guilt, although she is not, of course, morally guilty. An illness, being a hard experience, demands a realistic attitude and an effort to endure and cure it. But mental deficiency is, in general, an irreversible situation and needs constant care. The necessity to care for those people for their whole life, till their death, causes animosity—it is much easier to find people who are ready to help others for some time than to be always ready to help. In the Polish experience, those who care best for the handicapped are the religious people who regard the life of sacrifice as their vocation. Institutions caring for the handicapped run by religious orders ensure to those children, in general, acceptance and love.

5. Rehabilitation

Parents of handicapped children begin, in time, to perceive some advantages of their situation while observing the influence which the presence of the child exercises on themselves and their environment. The change of their attitude takes place more readily where their situation has been accepted by their milieu with benevolence and help; such a change may be perceived, in particular, among believing Catholics.



Most significant are the testimonies of people who confess that, although in the beginning they had felt a grudge against fate or even against God because of their ill child, they realized, with the passage of time, how much the child has contributed to the deepening of their worldview and of their faith; because, in the light of faith, suffering is the factor which purifies human hearts. John Paul II said that the suffering of innocent people was the greatest mystery of God and that this mystery cannot be understood—we must just accept it. And the acceptance of " one of those lowly ones "—and an ill child is such a lowly one par excellence —is always the acceptance of God Himself; believers find in their difficult situation an infinite value.

In this respect, very characteristic was the pronouncement of the International Association of Parents of Handicapped Children in France when the French parliament voted in the new law on abortion; they were the first group of citizens who protested against the killing of unborn children; they stated, for example, that an ill child brings more happiness to them than the healthy ones, because he is grateful, answers a smile with a smile and does not demand anything. Moreover, they asserted that the existence of those helpless and unproductive people in society is an important factor in keeping the " balance of the world, " in the preservation of true humanity in the human family; that, without them, who by their very presence impose altruism on the world, who make people render free services to other people, the world of the 20th century would be inhuman in its ruthless materialism. The handicapped remind the world of the existence of values other than material ones.

Indeed, society is, so to speak, " forced " to help those people.

A handicapped child living in a family needs not only the care of its family alone; it also needs expert medical care. Physicians and psychologists are needed in order to find the proper way of dealing with the child. This fact appeals to the good will of the physicians and, on the other hand, to the social system, which should provide not only proper care in the respective institutions but also free medical care at private homes; a network of such institutions is necessary.

The sick child has also a positive influence on other children, who learn to help others and thus conquer egoism.

Sometimes a handicapped child, in particular one with extensive impairments, dies soon and the family reacts emotionally to the death; this seems to direct our attention to the permanent values; everybody must die and go back to his Creator—regardless of his being a believer or not and independently of his own will. The contemporary world, stigmatized with its pursuit of conveniences and trying to avoid suffering at any price—this manifests itself, e.g., in the practice of euthanasia—must, nevertheless, accept the necessity of dying. Reflection on the inevitable end of the biological life helps us to look deeper into the goal of human life; for believers to die means to go back to the Creator and to be judged by Him; it also means to attain the felicity which " Eye has not seen, ear has not heard, nor has it so much as dawned on man " (*1 Cor* 2). The presence of an ill child makes the family think about God and about eternity and thus fosters the sanctification of this family; and, when the child is baptized, his presence means the presence of a saint in this house—the ill child does not do any evil. A mother of a boy with Down's disease said at a symposium that, although in the beginning she had rebelled against God because of her ill child, now she had learned that her son was a blessing to her family; because of his presence, all its members have become better. It is very true that children often bring to their parents great sorrows, but it is not true that healthy children bring only joy. I have learned in my long practice in a counseling center for so—called " difficult children " how much pain is given to their parents by children who are quite healthy, but who lie, steal, and do not respect their father and mother. Parenthood is always connected with toil and demands sacrifice.

But the optimal situation in which the whole family accepts an ill child does not always occur.

Anyhow, a family with a handicapped child always needs help.

This help is relatively easy to realize when the child is impaired to such an extent that he remains for ever on the level of a baby and needs simply constant care. But it is much more difficult in cases when a person with a very low intelligence quotient is growing up and does not appear to be different from normal people, while, in fact, he or she is incapable of moral evaluation and subject to bad influences. The investigations of juvenile delinquents and prostitutes show that a great percentage of those persons are mentally deficient; they are a serious problem for society, and when they have grown up, the family may be unable to have any influence upon them.

6. Society and Incurably Ill Children

The existence of incurably ill children compels the state to initiate actions which would help their families. Besides pecuniary benefits to the disabled, the society must organize a net work of institutions whose task is to help them—both those in which they would live and those which would provide them with proper care at home. To make this possible, there must exist a body of specialists—physicians, psychologists, teachers trained for this particular purpose—a net work of schools with programs which are adapted to the needs of the handicapped, i.e. aim at the development of the abilities of disabled persons.

But the first, basic condition for proper care of those people is to secure their life, legislation which would not allow them to be killed, which would forbid killing a conceived child because of disease.

7. The Church and the Handicapped Child

For centuries, the Catholic Church has striven to help, in its pastoral service, everybody who needed help. Throngs of religious have taken care of the ill, the disabled, the abandoned. This function of the Church is still alive and the practice of life shows that, in many countries, the Church is the only force which cares for the fate of the injured and of those who have suffered injustice. Initiatives of lay Catholics, supported by the pastors, seem to be the proper way to realize this task.

Houses of communities, where the handicapped find help and friends, vicarious families, meetings of prayer and pilgrimages—those are the initiatives in question and, fortunately, their number in the world grows. Hagiography is full of saints canonized for their self-sacrificing work for disabled people.

The particular solutions in different countries vary, but everywhere the presence of handicapped children appeals to human hearts; the problem of all the the handicapped persons cannot be solved by legislation and paragraphs alone—the only human way of approaching them is to acknowledge their full humanity and to oppose discriminating against them, to teach people to recognize their neighbor in each of them. Catholic ethics and the Christian faith give a full answer to the question of how healthy people should treat the handicapped—this answer is the commandment of love—Christ identified himself with them. To perceive in those people God Himself—this is the basic task for the Church, not only for the hierarchy, who can create charitable institutions, but for all members of the Church, for all Christians.

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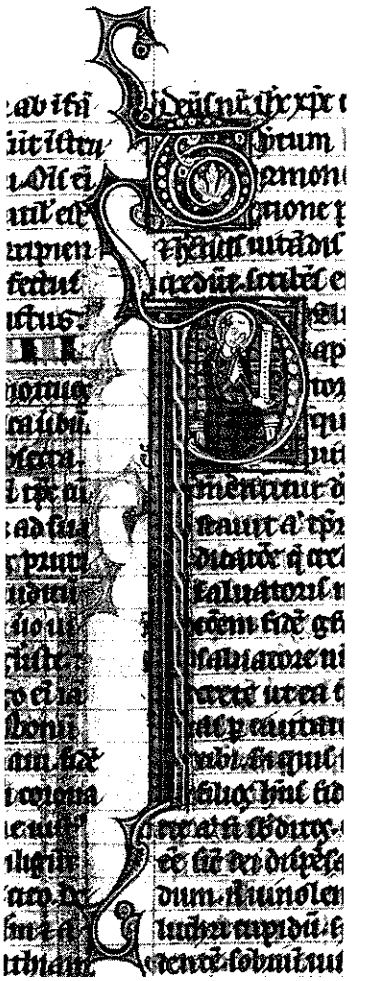


EDOUARD Cardinal GAGNON

The Church's Presence and Action in the Family of the Handicapped Child

The two previous conferences made it very evident that an institution like the Church should be present in the life of the handicapped child and his family.

In order to understand the Church's perception of her role, it seems to me to be necessary to bring to mind, first and foremost, certain guiding principles of her action, and to then show certain examples of service that she offers or would like to offer to the family of the handicapped child

Principles

The first principle of the action of the Church is her faith in the human person: man owes his life to the creative act of a Father God who personally wanted man to come into being After the vicissitudes of the present life he gives man up to an eternal destination. Christ died on the cross in order to make this destination one of perfect happiness.

The Church recognizes that this imposes on her, and imposes on each and every one of her members, the responsibility of contributing to the physical, spiritual, and social health of everybody, and in particular the weakest and the poorest of our brethren.

Another principle of the action of the Church is her faith in the family, the cradle of virtue, the fundamental cell of society, and the school of social virtues which are the soul of the life and development of society (F.C. 42).

The Magisterium of the Church gives practical expression to these principles in affirmations which, most of the time, are like those which draw upon the wisdom of the world's peoples. An illustration of this last is to be found in the Universal Declaration of Human Rights.

To commemorate the International Year of the United Nations for the Handicapped, the Holy See published a document which, despite the fact that the Holy Father has repeatedly drawn attention to it and emphasized its importance, is not sufficiently well known. It contains the following observations.

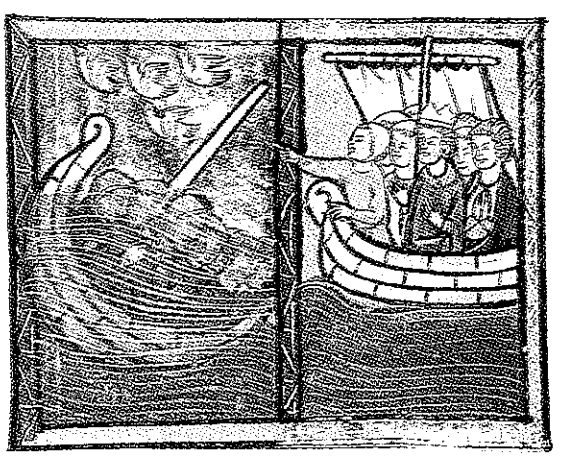
— The handicapped person is a fully human subject with all the natural, sacred, and inviolable rights which correspond to that status. We must help him to take part in the life of society in all its dimensions and at all levels which are open to him according to his abilities and capacities.

— The quality of a society and a civilization are measured with reference to the respect that they show towards their weakest members.

— It is necessary to surround the family of the handicapped person with a climate of understanding and sympathy

— Handicapped people have the right to live with their families or in a family environment.

— The institutions which take



the place of the family must take after the family model and avoid all forms of segregation and anonymity

— " The handicapped child or young person has the right to guaranteed education, insofar as it is possible, in normal schools. It is necessary, thereafter, to take great care over the move from school to integration into society and professional life. "

(Secretary of State, March 4, 1981)

The Declaration of the Rights of the Family which was published by the Holy See following a request on the part of the Synod of Bishops on the Family and was then sent to all the heads of state of the world, makes, in turn, the following series of statements.

— Children, both before and after birth, have a right to special protection and help. The same rule applies to mothers, both during pregnancy, and for a reasonable period after birth

— " Handicapped children have the right to find a suitable environment for their human development at home and also at school " (October 22, 1983, art 4)

These declarations of the Holy See also reflect the thought of the local churches. The Spanish bishops, for example, wrote in one of their pastoral letters: " The declaration of the United Nations on the rights of handicapped people specifically maintains that handicapped people have the right to live with their families or in a family environment (no. 9). We should stress the validity of this affirmation in energetic fashion. To put it into practice, it is indispensable to give technical and moral assistance and support to the families of handicapped people from the first diagnosis of the condition and regularly thereafter; to give them economic support through a correct recognition of what care for a handicapped child means for the family budget; to ensure, where an institution is involved, that special attention is paid to the importance of contact with, and the presence of, the family with that institution; and to make certain that within this institution the atmosphere and overall organization are good and that the institution itself, insofar as it is able, strives always to imitate and follow the family model. "

Practice

Catholic institutions, over the centuries, have been in the forefront of care for the infirm and the sick of all kinds. A large number of these institutions have devoted special attention to children. The investigation currently being carried out by the Pontifical Council for Pastoral Assistance to Health Care Workers will make clear that these institutions are still necessary, above all else in those societies which are less advantaged. Even in Europe, in a country, for example, where the state makes a great effort to be responsible for health care and education there are still over thirty communities devoted to achieving the social integration and development of handicapped people.

The Italian episcopate's acknowledgement of the value of these institutions, which are even more numerous in Italy, is not a matter of mere self-congratulation: " Many male and female members of religious families, during the course of the history of the Italian Church, have received the divine gift of bearing witness to the compassion of Christ for the infirm and for those who suffer. In frequently performing supplementary work in society when public action was inadequate, these families have opened up new routes by which to help the sick and achieve the rehabilitation of the handicapped. They have thus educated the people of God in the acquisition of an evangelical awareness and sensitivity towards new needs, to which an answer has not yet been found " (March 30, 1989).

The Church invites existing institutions to accord a greater role to the family, to have faith in the family, and to involve the family in her work. The Church also insists again on everybody, and Christians in particular, being called to pay direct attention to the needs of the families of handicapped children.

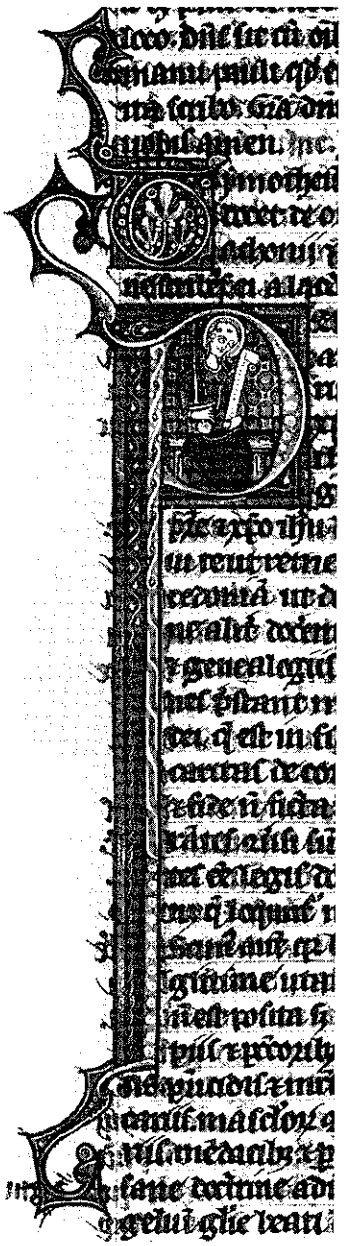
Governments themselves are concerned with what the family can do with regard to solving social problems. Invocation of the responsibility of the family on the part of politicians involves the hope that the financial budgets of their respective countries can be reduced

and that the costs of their national health care systems can be eased. But there is something else. Paul VI seemed to be a voice in the wilderness twenty years ago when he affirmed to international audiences that nothing could be achieved of a lasting and permanent character without the family. Ten years later, the assembly on the problems of the elderly recognized that in Northern European countries, where the public systems are at their most all-embracing, 80% of elderly people are still the responsibility of their families. It also observed that, taking everything into account, it is much more economic and cost-effective to help the families involved than to build and finance old people's homes.

This is even more true with regard to handicapped children. The Church knows this very well. In inviting governments to help these children with greater realism, she feels with ever greater intensity the need to make people more aware of the question, and to promote and foster initiatives which will ead to development in this area.

The first duty of the Church is to proclaim that a man cannot have a Christian heart if he does not open his eyes to the needs and the desperation of families and their handicapped children. The Pope is their first advocate. None of his great writings fails to mention them. During his apostolic journeys he always strives to meet handicapped children. He tells them to trust to their prayers and their generosity in accepting their suffering and the limitations to which they are subjected. For them and for their parents he raises a corner of the veil which covers the mystery of the suffering of children. He draws attention to those heroic reserves of love that such suffering can give rise to, to that rising above oneself that such suffering can teach, and outlines that wider vision of the eternal destiny of man which leads us to discover the understanding of pain in its deepest sense—something we do by taking Christ's suffering as a point of departure.

Just as at the time when these institutions and communities were established, there have always been prophetic and magnanimous people



who have seen a need and have given grass-roots, arduous impetus to initiatives they think are necessary. These people often seek the Church hierarchy's approval for their actions and they are given community or other kinds of structures aimed at ensuring the continuity of their work.

It would not be appropriate here to mention all those associations or movements which operate to considerable effect in the field under discussion here. It is sufficient to give a number of examples.

The bice has informed us about the special work it performs to help families and handicapped children to break out of their isolation. The Silent Workers of the Cross inform me that in the Holy Land they also deal with the problems of parents who are ashamed of the condition of their own children.

Notable work is carried out by The Ark and by Faith and Light. It is necessary to have been present at one of the great pilgrimages organized by Jean Vanier and his assistants to see how they have been able—through faith—to give new hope to handicapped children and their families. This hope is expressed in songs and unforgettable smiles.

Every Holy Week of every year I accompany a group of four hundred Volunteers of Suffering to Lourdes. Many of them are children with their families. There, as well, where Mary is present, hope and joy reign. In this case as well, as in that of the English HCPT (Handicapped Children's Pilgrimage Trust) groups, the pilgrimage is the expression of an activity which takes place for the whole of the year and which aims, first and foremost, to support the families.

In the field of spiritual promotion, reference should be made to AFALE (in English, Family Action for the Evangelization and the Apostolate of Childhood) and the Christian Brotherhood of the Sick and the Disabled. Both these organizations are directed by the handicapped themselves.

The Knights of Columbus have one and a half million members in America and the Philippines. In carrying out their charity work they give priority to families who have special needs. They take the place of parents for a while so that they

can relax through cultural or sporting activities. They organize special holiday camps, obtain places to live, furniture, orthopedic instruments, and so forth. They dedicate millions of hours to these families.

There is no lack of initiatives and pastoral projects on the part of the ecclesial structures. The diocese of Patti in Sicily, for example, has joined with the University of the Sacred Heart to create a service to teach the mothers of mentally afflicted children to develop abilities in their offspring which they previously thought impossible right from the early months. So much has been achieved that some of these handicapped children, on reaching school age, have been able to join other children of the same age.

Encouraged by the appeals of the Pope and by his pastoral council, the bishops are gradually creating services which cater to the very different needs of the family within which the handicapped child must grow up. These services, which are being set up at a diocesan level or by the bishops' conferences, contribute to an increase in awareness of this general area, act to promote action, and provide practical help.

Here are some of the objectives proposed to the Christian community by the Australian episcopate. Some of them are already undergoing implementation:

— the preparation of guides or catalogues in which families can obtain information about the services which are available to them in institutions and through government;

— the publication of books and bulletins which provide parents and educators with practical advice on the best behavior to be adopted towards these children and the best means by which to develop their personalities and their talents;

— the promotion of initiatives to enable the families of handicapped children to help each other and to enable other families or people who have the possibility of doing so to be present with the children either in the home or outside and thus to give the parents a moment of relief or to help mothers with their most arduous tasks;

— to secure the opening of recreational or cultural centers which are suitable for the different members of the family;

— the creation of centers of early diagnosis—where these do not already exist—and offices where parents can go and receive advice of a medical, psychological, pedagogic, and spiritual character.

Conclusion

The conclusion can take the form of the report presented to the Catholic Commission of Social Welfare in this country:

" The evolution of activity (in this area) has been determined with regard to its direction by the identification of the needs and the presence of personnel who ensure that the services deal with these needs. Development came very much before the formulation of strategies and the organization of Gospel values by which to guide this development, to regulate the strengthening of these services, and coordinate pastoral programs. It is clear that the Church, at a diocesan level, must consider the formulation of such plans an urgent task " (April 1985).

The pastoral challenges which will arise will always be new. We do not need to wait for great measures of planning to respond to these challenges. A certain coordination of the initiatives which are embarked upon will, however, ensure that they are more effective.

EDUOARD Cardinal GAGNON
President of the Pontifical Committee for International Eucharistic Congresses

THOMAS H. WELLER

Handicaps Resulting from Infectious Diseases

A consideration of the handicapped child usually focuses on the problems of the affected individual. That is the logical focus of the concerned parent and of the personal physician. Less often is there consideration of the handicapped community of people, the logical focus of those concerned with the welfare of populations. My presentation will deal with the individual and with the community. In terms of sobering statistics, it is the community that deserves emphasis.

A symptomatic infectious disease induces a transient or permanent handicap. Death is the ultimate handicap. The occurrence of handicaps due to infectious diseases reflects the complex interactions of the elements of the classical epidemiological triad, i.e. the *human race*, which is rapidly increasing in number; the *agent*, which includes the spectrum of virologic, bacterial, protozoal, helminthic, and fungal pathogens, entities that may be genetically unstable; and the *environment*, our earth spaceship, that we are progressively degrading. Each element of the triad is changing with an ensuing continuum of new problems. New knowledge reveals previously unrecognized deleterious consequences of old problems. In this presentation we will selectively touch on ongoing changes that modify the deleterious impact of infectious diseases.

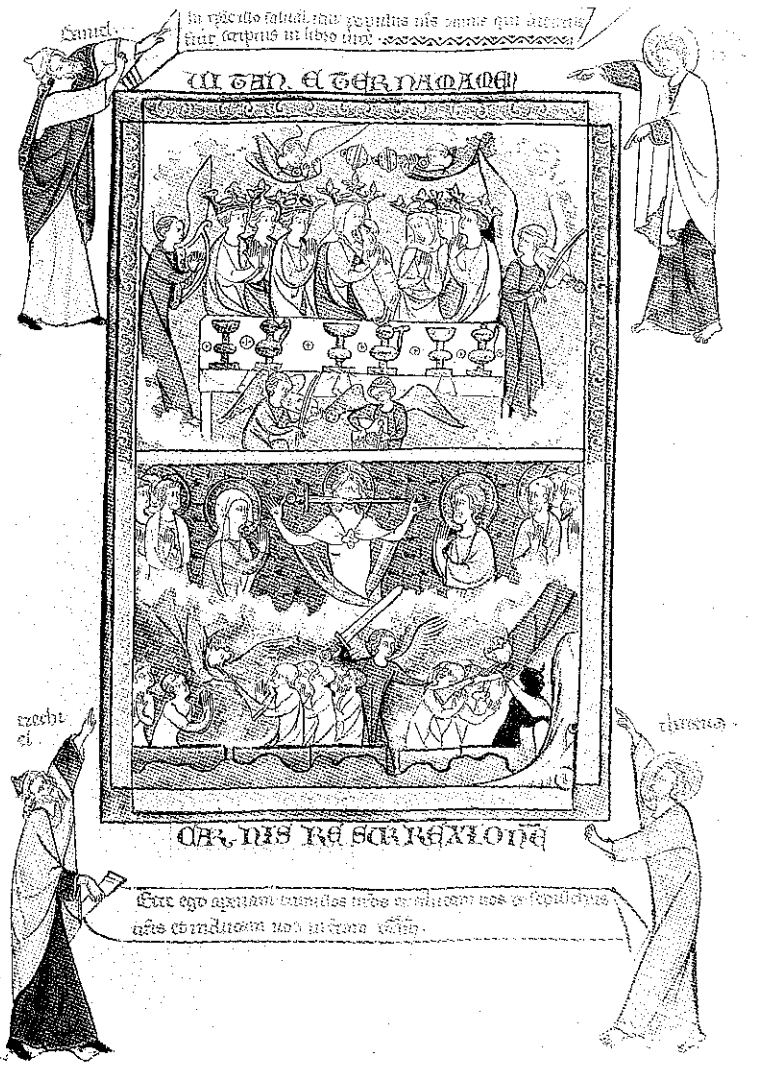
Theoretically, we should be able to greatly reduce the incidence of handicaps due to infectious diseases. The application of specific preventive vaccines and the use of an expanding number of effective drugs may prevent or treat infections. We know how to obtain environmental control of some infectious entities. Recent successes, examples of which are cited, are a source of satisfaction but may promote unjustifiable optimism.

In the vaccine area the global eradication of smallpox achieved in 1977 was a magnificant accomplishment. Currently, multinational and philanthropic agencies are united to achieve the eradication of poliomyelitis. During the past 12 months not a single case of poliomyelitis has been reported from all of the countries of North, Central, and South America (1).

The World Health Organization has now officially scheduled dracunculiasis (guinea worm disease) as the next entity to be eradicated, an example of control by environmental modification. This parasitic disease is caused by a nematode that produces incapacitating foot or leg ulcers. Some 100 million persons are at risk in more than 20,000 villages in India and Pakistan, and in some 17 African countries (2). The larval stage of the worm develops in small " water fleas " (copepods); people are infected by drinking water containing the copepods. Control depends on providing alternative copepod-free water supplies, either by killing the copepods with chemicals or by simply removing them by filtration of drinking water through a nylon mesh filter. Already the disease has disappeared in several countries.

Signal successes have also followed the introduction of new chemotherapeutic compounds. For example, the treatment and control of schistosomiasis have been revolutionized by the introduction of the oral schistosomacide, praziquantel. The filarial disease onchocerciasis is the fourth leading cause of blindness globally. The major locus is in sub-Sahara Africa, where some 20 million people are infected (3). Until recently control was based on elimination of the black fly vector by larvaciding the fast-flowing streams where they breed. In the highly endemic Volta River basin this logistically difficult operation costs the supporting consortium of international agencies $20 to $30 million dollars a year. The recent introduction of the first effective drug, ivermectin, offers a new approach; already some two million people have been treated.

However, such signal advances should not be the the basis for optimism regarding the capacity of society to eliminate handicaps resulting from infectious diseases. In the developed world research continues to expand our knowledge. For example, years ago in 1956 we isolated a new virus from a brain-damaged child and coined the name cytomegalovirus (4,5). The serious delayed effects of this disease have become apparent much more recently. It is now established that each year in the United States some three to four thousand infants are born with a symptomatic cytomegaloviral infection; the survivors are usually mentally retarded, blind, or deaf. In addition, each year some four to six thousand congenitally infected infants who appear normal at birth develop deafness or other problems later in life (6). At present we have no effective preventive or



therapeutic measures for congenital cytomegaloviral infections

In the peoples of the developing world the mass misery produced by repeated infections often complicated by malnutrition, in the presence of inadequate health services, precludes a proper assessment of the handicaps due to infectious agents. Even well-defined clinical entities may be missed. For example, 35 years ago we taught that clinical poliomyelitis was rare in the tropics. As reviewed by Crawford and Hobbs (7), this erroneous belief changed when lameness surveys revealed a high prevalence of paralysis. In Uganda only leprosy caused more deformity. The World Health Organization estimates that 250,000 new cases of paralysis occur annually in the developing countries.

Research is also redefining the frequency of disabilities induced by other common infections. Malaria remains endemic, particularly in Africa, where malaria is estimated to kill more than one million people a year, the majority of deaths reflecting cerebral malaria due to *P. falciparum*. Formerly we believed that the millions of people who survived an attack of cerebral malaria rarely had neurological sequellae—a view altered by recent studies. For example, Bondi (8) studied children with cerebral malaria hospitalized in Ibadan, Nigeria in 1987 and 1988. There were 62 survivors among the 78 patients; neurological defects, including cortical blindness, monoparesis, and speech defects occurred in all of the 62 survivors.

Many pathogenic agents are genetically labile and antibiotic or drug induced pressures promote the replication of resistant organisms. Over the past forty years successive generations of therapeutic materials have lost curative power. If effective alternatives are not forthcoming, the situation may be catastrophic. Two current examples are illustrative. The lethal malaria species, *Plasmodium falciparum*, has developed resistance to chloroquine, the mainstay of treatment for thirty years; resistance has also developed to old antimalarials, such as quinine, and to new compounds such as mefloquine. No adequate alternatives are in sight. Tuberculosis is now resurgent as strains of *Mycobacterium tuberculosis* have emerged that are resistant to isoniazid and to rifampin, the two current effective drugs (9). Outbreaks of multidrug resistant tuberculosis are now appearing in institutional settings with frequent transmission to attending personnel. Even before the emergence of resistant strains, it was estimated that 7% of deaths in the developing world were due to tuberculosis (10).

In addition to the problems posed by classical pathogens, we should anticipate that new entities, such as HIV-1, the cause of AIDS, will appear and be a major cause of handicaps. The ramifications of HIV-1 infection rates that range from 10% to 30% in cities in sub-Saharan Africa are sobering. For example, most Africans are infected with tubercle bacilli; in the presence of AIDS the latent infection becomes active. Surveys have shown that between 20 and 67% of individuals in Africa with AIDS —have active tuberculosis.

It is not generally appreciated that AIDS may handicap large numbers of children who are not infected with the virus. I refer to the orphaned children of AIDS infected parents. It is estimated that about 70% of infants born to infected mothers will escape the virus. Such infants are doomed to

be orphans. Dr. Jonathan Mann, Director of the International AIDS Center at Harvard, estimates that currently 1 7 million children in Africa have been orphaned by AIDS, and that by 1995 the figure will rise to a staggering 3 3 million (11) The numbers are far beyond the caring capacity of the traditional extended African family; for the majority, life will be grim indeed.

We have discussed problems associated with infectious agents These problems are enhanced by changes in the human host and by the progressive degradation of his environment. The host, humankind, is rapidly increasing in numbers—almost 100 million people every year. This human replication has two characteristics that amplify the impact of infectious agents. First, about 95% of the population increase is in the less developed countries. Secondly, and particularly in developing countries, the effects of this increase are compounded by the tremendous redistribution of peoples, reflecting massive migration from rural to urban areas A characteristic of the resulting large cities is the rapid proliferation of huge slums where the inhabitants live in squalor, often lacking potable water and even rudimentary sanitary facilities The Population Crisis Council (12) points out that whereas in the past industrialization stimulated urbanization, the current stimulus is poverty resulting from overpopulation of rural areas and associated environmental degradation due to overcropping or overgrazing Currently, Africa's urban population is growing at 5% a year, representing a doubling time of only 12 years

While the situation in the developing cities is well documented, vital statistics derived from studies in rural areas are rare. Between 1973 and 1982 we carried out a population-based study of Chagas' disease in an impoverished rural area in the state of Bahia, Brazil (13). An annual census revealed a yearly out migration of about 10% of the population, most often to the slums of the major city, Salvador. Chagas' disease reflects poor housing and poverty Interestingly, individuals seropositive for Chagas' disease migrated more frequently than those seronegative. Over the nine-year period 52% of the 463 seropositive individuals emigrated

The implications of massive human populations living in squalor were succinctly summarized years ago by the famous American microbiologist Theobald Smith (14) when he wrote: " Large numbers of hosts furnish the starting points of epidemics, and nature reduces the superabundance of wild life through disease. Nature can be said to abhor a crowd "

A standard technique of epidemiologists studying infectious agents is to place susceptible animals or birds in environments where they would be at risk and then to study the acquisition of the infection—the so-called sentinel monkey technique. When a new agent invades a human population, the whole population serves as sentinels, an unstaged experiment of nature that sheds light on the complex interrelationships of the agent, the host, and the environment Such occurred in January 1991, when cholera appeared in the Americas after a 100 year absence (15) Cholera is spread through the ingestion of water or food contaminated with infectious feces. Cholera is therefore a glaring indicator of the inadequacies of the densely packed slums of cities in developing countries. By August 1992, the disease had spread to 18 countries in the western hemisphere, and by that date 645,037 cases had been reported with over 5000 deaths (16). Parenthetically, whereas formerly the mortality rate from cholera was around 20%, the introduction of inexpensive oral rehydration therapy (ORT),—so effectively promoted around the world by UNICEF, has reduced the fatality rate for cholera to around 1%. It has been estimated that to eliminate the risk of cholera in the western hemisphere by improvement of water, sanitation, and health services would require an investment in excess of $200 billion dollars over the next twelve years (16). The current explosive spread of cholera in the impoverished urban agglomerations of the Americas, aptly termed by Prof Rex Fendall " the septic fringe " (17), reflects Theobald Smith's conclusion that " nature abhors a crowd. "

In summary, the infectious diseases remain the major cause of transient and of permanent disability. Scientific advances have prevented some major killing diseases of children as, for example, the increasing use of vaccines for polio, measles, tetanus, and whooping cough, a program effectively promoted by UNICEF. The increasing use of oral rehydration decreases mortality due to diarrheal disease but not the prevalence thereof. Unfortunately, bacterial infections are becoming resistant to commonly used—and relatively cheap antibiotics.

At the community level prospects for the reduction of the prevalence of handicaps due to the gamut of infectious agents cannot be viewed with optimism. The problems of providing adequate housing, sanitation, health facilities, education, and food for the rapidly increasing population in the developing areas of the world have no obvious solutions. Meanwhile, these problems increase as the human host rapidly degrades his environment. There is an urgent need to inform decision makers and the general public of the increasing prevalence of human misery that nears the crisis stage. The presidents of the U. S. National Academy of Sciences and of the Royal Society of London have recently issued a joint statement on the matter. Under the auspices of the Union for Concerned Scientists, a statement entitled "World Scientists' Warning to Humanity" has been prepared that outlines the stress on the environment and on essential resources posed by mismanagement, overconsumption, and continued population growth. Shortly to be released, the statement has been signed by many senior members of the world's scientific community. It is our responsibility to join these initiatives in the education of those leaders who are in a position to influence the future of humankind.

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MARIE-ODILE RETHORE

The Announcement of Handicap

The growth of a child presupposes that he is accepted, recognized for what he is, and loved for what he is, without comparisons being made with other more or less intelligent, more or less beautiful, more or less affectionate, and more or less lovable children.

Herein lies the importance of what happens when a family learns that the child who has been waited for with such fervor, and cuddled with so much tenderness, is " not like other children. "

I know through having experienced such an event very often how very uncomfortable this situation is. It is certainly true that there is no good way by which to tell those terrible words which affect not only the life of a child but also that of the whole family—from now on nothing will be the same again for the people involved

It is not a question of consoling at any cost, of speech which learned words make comprehensible only with the greatest difficulty, above all when hearts are broken. Nor is it the right moment to make predictions of a gloomy character.

What one should do is to take the time necessary to show how things really stand; to describe the situation with simple words; to talk about what you know and to make clear what you do not know; and to answer questions, even if these have just been formulated, but to do so without going beyond the area covered by the question. One should tell the truth, but not necessarily all the truth at one time. It is necessary to adopt a listening attitude to the parents and to encourage the parents to say those words that they are afraid of hearing. In this way, the truth of the situation will not fall like a guillotine blade, destroying all hope completely. It will not be heard as a condemnation to a hard destiny. When the truth is said by the parents, at the right moment and with the words that they have chosen, it will free them from the anxiety, the uncertainty, and the difficult wait which the diagnosis involves.

This meeting, with its intensity of suffering and truth, is not a kind of parenthesis during which time stops running and the hierarchy of values is transformed in final fashion. It creates an exceptional bond between the person who accepts that he should tell the truth and those who receive it. It is, indeed, the beginning of a journey, of a relationship, and of an alliance in which each one of the partners has rights and has duties.

Who should speak this truth? Most of the time, it is a doctor, but not always. Which doctor? The one dealing with maternity where the baby was born? The family doctor? It does not matter very much, perhaps, as long as the person is tactful (something that is not learnt from books), has time (something a surgeon or an obstetrician does not always have), and above all else, as long as he can guarantee continuity in the relationship.

It is not possible to regulate things at once or in a single day. It is never over. Parents of adult children will not contradict me—it is the story of a whole life! Nothing matters except the construction of a warm net around his family in full respect for its intimacy

The in-depth clinical exam of the child, the carrying out of the necessary tests, the involvement of specialists—all this is clearly indispensable in the formulation of a diagnosis and genetic advice and should be effected as soon as possible and in reasonable fashion.

Rather than designate certain places, propose a program of re-education or schooling (something that will come in its own time), announce what the child will be able to do or will not be able to do at this or that age, one should, right at the outset, organize everything in order to discover the personality of the child—the child's aspirations, defects, limitations, and secret—and in going about this the parents are in the best position!

It is Gianluca and Natalia that they must discover and there is no need for books in such a process! If there are certain words which must be erased from our vocabulary, and above all else from our hearts, these are " those children are...sweet, " " affectionate "—as if microcephalia, meningitis, or the trisomy 21 syndrome paralyzed forever in the form of a monolithic species!

Discover the child in order to allow him to become what he really is; make him lovable, capable of love, enjoyable to love; allow him to be happy through the happiness of others; help him to make friends, real friends with whom he can really have an exchange because they have the same difficulties as he does; teach him to defend himself rather than correct those who want to attack him—here is the duty of the parents, indeed, of all parents.

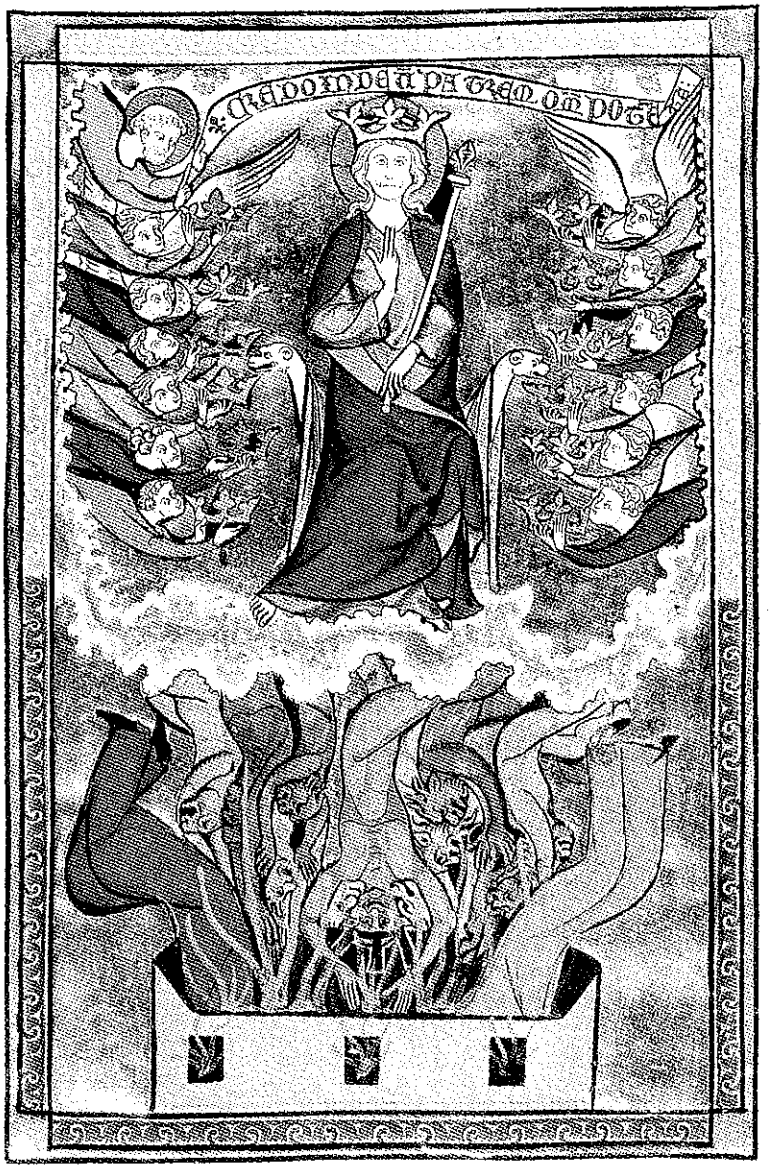
If the child is affected by an illness or a constitutional, and therefore unchangeable, infirmity, then the parents must do what is necessary to make sure that he benefits from social and financial policies designed for handicapped

children. All this should be set in motion as soon as the diagnosis is made. One is not here dealing with asking for a favor or asking for charity. It is a matter of justice towards a handicapped child and his brothers and sisters. Why, for example, wait for a child affected by the trisomy 21 syndrome to reach a certain age before giving him an invalid's card so that the parents can take out a particular life insurance policy? This child will need to be protected throughout his life, as we well know. The parents do not live forever. Accidents do not only happen to other people. Why wait, therefore? But the parents will always have to deal with bureaucratic problems.

The ideal environment for the growth of the child is, without doubt, the family. But each case is a special case. There are families which cannot have a handicapped child because of the age or the state of health of the parents, because of the number of brothers and sisters and their state of health, because of the condition of the home, the financial situation, and the seriousness of the child's illness. All these elements which make up the history of a family must be taken into consideration. What may seem the best solution at one particular time may not be so a little later because the child has achieved certain advances or because the illness has developed in a certain way, or the situation of the father has changed, or the health of the parents is no longer what it was, etc. It is then necessary to re-examine the facts of the matter and find a new modus vivendi which, in turn, will not be final.

It will be a good idea to entrust the newly born child to a nursery as soon as he is out of the maternity ward. This stay of a few weeks will allow the parents to recharge themselves in calm fashion. They will, perhaps, be more ready to welcome the child. The child, himself, after the first few days, will be able to take food more easily. There is nothing more discouraging for a tired and sad mother than to see her own child sleep rather than take her milk.

The arrival of the child in the house should not upset everybody. He has been expected for many months, and the parents have foreseen that they would have to change their way of life because of the child. If the mother decides to start working again after the initial period, the illness of the child should not make her change her mind. He will be entrusted to a nurse who is an expert but not necessarily a specialist. On no account should the child become the center of the home around which the other children are asked to gravitate. The parents and the brothers and sisters should not live according to the rhythm of the sick child; it is he who should be gradually integrated into the family and its rhythm. This is possible as long as the center of the home remains as it was—that is to say, the love that unites the parents and the siblings. The weight of the sick child will thus be borne by everybody and not only by the mother. Very often there will be a more or less confused awareness of the child's difficulties and limitations. Here again, if one wants to avoid serious crises when the child comes to realize the nature of his condition, then the obvious must not be hidden or denied. It is necessary to accustom him very early on to hear the name of his illness. This will not frighten him if said by his father or mother in a tender and simple fashion during everyday life, or, if he asks, in a more explicit way.



With regard to the brothers and sisters, at all costs one must avoid the illness being communicated to them in the wrong way, and in a

bad way, by another child. This assumes that the parents explain the illness to them with simple words and insist on the fact that it is known, that its name is known (and its name should be given), and that the doctors do what they can to treat this illness—the brothers and sisters taking part in this operation.

Whilst the other children can help their younger brother very much and to much effect, merely by playing with him, singing, talking to him, and so forth, too much should not be asked of them. Taking care of an unstable child is often too great a task for a bigger sister, whose authority, which is still uncertain, can be questioned. Accompanying a handicapped brother for a walk can be a real trial when there is a fear that a classmate will be met " who does not know. " One should avoid always saying that the sick child is right and turning meals into a meeting between parents of handicapped children. Every now and then the sick child should be entrusted to a third person so that the parents can have a rest or the other children (or one of the parents, why not?) can have a holiday. Given these conditions, the presence of a handicapped child in a home, far from disturbing the other children, will allow them, day after day, to learn to respect people who are weak, subject to deprivation, and love those who suffer.

The older children should be told that preparations will be made for the future of a handicapped child and that the child will not be a burden on them when the parents are no longer alive. Liberated from such fears, they will be ready to surround their brother with affection and welcome him to take part in holidays. Holidays, indeed, are often the occasions for a great deal of loneliness.

One must know how to tackle certain questions. Many young people worry about children. They do not dare to talk about them to their own much burdened parents. They reject the idea of marriage and procreation. We have already said that in many cases it is not possible to allay these anxieties. Here also it is necessary to talk to a doctor before it is too late.

A home cannot be a closed universe: otherwise it will inevitably suffocate. As soon as it receives a breath of fresh air, its light and its heat will slowly spread. For this reason, the break with the initial state of relationships and with the family in the widest sense of the term condemns the home to being a world apart which quickly becomes a hell. In this hell the child becomes the principal victim because he is condemned to languish in the state he is. It is often the attitude of the parents which enables others to enter the door and make the burden more tolerable by sharing it.

It nevertheless happens that we often feel rather embarrassed, especially at the first visit. Should we go to the maternity ward? Should we take a present, some flowers? Should we make clear that we know or not? Should we speak about an association for the parents? When? How? There are so many questions without ready answers.

I think that one must act in line with what one's heart feels—discretely and simply. One should speak more than listen, wait rather than impose, respect the silence even if it is lengthy, be there when this is called for and go away when necessary.

Every doctor, every wise woman or nurse, should have access to telephone numbers which enable them to call, when appropriate, a discrete and effective person who can give information or advice or even take the place of an unknown and anonymous taxi driver.

The bringing of a handicapped child into the world is infinitely painful. Nothing and nobody can console such an event. Those who have the task of accompanying the parents, above all at the outset, have a very heavy responsibility. On their attitude, in large measure, depends the future of the child and the harmony of the home. The child will be put in a " home made for those children, " restricted to a condition of not being " like the others, " closed up within himself or, on the contrary, open up and flourish, sustained by the love of those able to discover his secret, the treasure which is hidden in his inner self, amd make him grow, day after day, before their eyes and the eyes of other people.

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ALESSANDRO BERETTA-ANGUISSOLA

Environmental Conditions and Risk Factors for Young and Adult Disabled People

I have come into contact with disabled people very often during my academic and medical career, both in a professional and a clinical capacity. Given that infants are the responsibility of those of my colleagues engaged in pediatrics, I have been concerned with young people and with adults. In each case, however, the purpose of my encounter with these disabled people was the assessment of a clinical problem or the diagnosis and treatment of an illness—something which is very common with these people, given their genetic inheritance and the factors often acquired through their environment (family, school, workplace, and life). A reductive vision of the person thus emerges: notwithstanding the obvious disability which presents itself to the observer, he is a patient just like the other patients.

Only much later, and for reasons which have nothing to do with professional considerations, does an encounter take place with the person to be found within the handicapped patient. There is contact with the extreme complexity of his human problems and with his diversity—something, however, which does not change his identity. Through this activity I have met a new world which, like the world of my clinic, is marked and characterized by infirmity. But it is much larger and more demanding—its roots are to be found in the mystery of man, his existence, and his purpose in life.

The use and abuse which is made of the term handicap, especially by the mass media, has acted to label the person who is disabled and in a way which does not only involve his abnormality. He is considered as somebody who is different. This is true with regard to his psychophysical disability, but it is false when applied to his inner person and his identity. The handicap is the product of biological damage, but the person within is the same as we ourselves and is the bearer of the same dignity. It is simply that his structure is more vulnerable. But it is precisely because this person within is like us that he asks to be accepted; and it is precisely because he is more vulnerable that he asks to be helped. He has exactly the same rights as we do.

The words of my dear friend Professor Lamberto Valli, who died some years ago from a tumor, come to my mind. In denouncing the fact that in today's crowded hospitals all-round care for the patient is often lacking—that is, of the spirit as well as the body—he asked himself the following: " What does the sick person in a hospital need above all else? Not commiseration, but solidarity. He needs to feel on the same level as others..., to be understood for what he really is—an individual who merely has some difficulties in the use of his body but whose humanity and dignity are intact, an individual who goes on being a living cell in our humanity. " The very same may be said for the handicapped person.

Does a culture of acceptance really exist? If one only takes into consideration the norms which in our country are highly advanced and are embodied in the legislation of February of this year—laws which were the product of an extensive legislative debate and a process of social and human advance—then the answer must be in the affirmative. But realities are very different and this is not something which should give rise to great surprise. The acceptance of the handicapped person is in conflict with today's ascendant culture—the culture of the perfect body expressed by the models followed by advertisements, television, and fashion. Furthermore, there is still strong resistance (if not rejection) to the idea that people who are not productive (or are so only in a partial sense) have a right to taking part in social life and in the world of work according to their abilities.

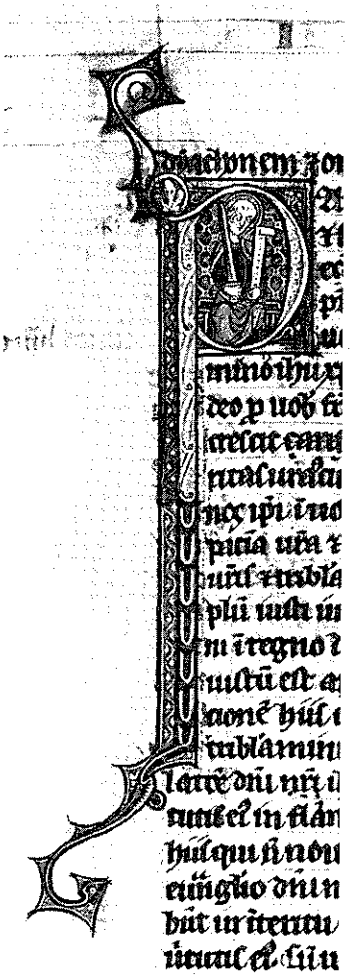
The words of John Paul II are of direct import here: " The quality of a civilization or a society can be measured by the extent to which it expresses respect for its weakest members. A society which is perfect in technological terms, and to which only those who are fully productive are admitted, should be adjudged as being radically unworthy of man and as being perverted by a kind of discrimination which is no less worthy of condemnation than racial discrimination. The handicapped person is one of us; he is a part of our own humanity. The recognition and promotion of his dignity and his rights means the recognition of our dignity and our rights. "

The handicapped person should be accorded full acceptance as an integral part of society. His " human " history, even though it involves diversity, is equal to that of every other man. This enjoins us to make a positive assessment of that physical and psychic richness—different though it may be from person to person—which is present in each handicapped person and which, with science and awareness, can be developed in ways that are

often unpredictable. This can take place in a variety of contexts, whether in the family, in schools, in the world of work, or in social relationships, and has been demonstrated by numerous real-life examples.

I have in my mind the children, young people, and adults of the Osimo Institute for the Blind and Deaf. They are people who are afflicted by multiple disabilities which are often not merely related to the senses. They are completely isolated from the rest of the world. They have only one way of experiencing the world about them —touch. And it is precisely through their hands, and through a very patient, well-tailored, continuous process of education, that they are gradually able to communicate with the external world. In this way they also acquire a relative self-sufficiency and come to learn some occupational and domestic skills. Some of them, both young and old, are integrated into the social and work environment of the town; some work and live outside the Institute and with the help of expert workers take care of their own needs. It is not true, therefore, that a child or a young person cannot have a history projected into the future and having a future.

I also remember, and this is a matter of personal experience, the socioeducational center of Urbino, where mentally retarded young people continue to be educated after obligatory schooling. They are also, if possible, directed towards a work activity under the guidance of enlightened teachers (Meazzini, Dacha, Cottini). As happens in many other such centers, I have seen disabled young people deal with the typing and binding of theses for the students of that university. Others take advantage of the laboratory of the Raphael Academy to do works of pottery and ceramics. One group takes care of the commercial activity of a stationers shop. All are involved in motor activities in the swimming pool or the gymnasium. There are many examples of such initiatives. Many great and marvelous works are carried out in institutions and in the privacy of a host of families. They seek to promote the development of the personality of the disabled person and to improve the quality of his life.



When confronted with these demonstrations of humanity and solidarity, I am led to reflect upon the culture of death which is present in our society and which is in antithesis to this culture of life. In how many people's opinion—and even doctors'—should an abortion have been carried out on these young people when still in the womb? Fortunately, things do not always follow such a course.

This short little story is about Chain, a child of nine years old (R. Battaglia). " We are flying the kites that Miss Suan helped us to build and to put up into the sky because today there is wind. The kites are multi-colored and fly very high, even that of the boy without hands who arrived yesterday. He holds the string of the kite in his mouth and smiles. We have put some tails on his kite so that it will fly higher than the others. " Without hands—what a miserable quality of life! But he is alive and perhaps he will fly higher than all of us!

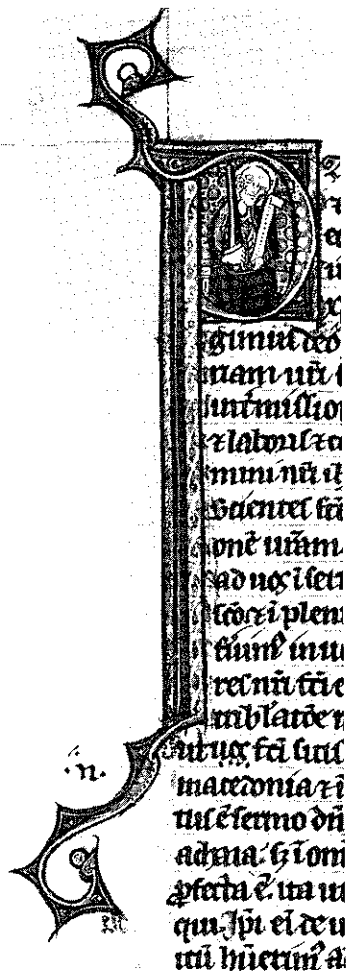
A great deal is said about disability nowadays. This is because finally, after many centuries of darkness (illuminated by the lights of Christian charity), its dramatic frequency has come to the misplaced attention of today's society. In speaking about it, we immediately think about a whole host of children afflicted by physical, psychic, and sensorial disabilities. These handicaps are obvious because in the vast majority of cases they show up in very early childhood—the consequence of biological damage which is either prenatal, or perinatal, or of the first months of life.

In this way, however, the condition of disability which is present in young and adult people becomes relegated to a secondary position. It usually comes to be considered a product of childhood—something which in certain respects is no less deleterious both for the disabled person himself and for the family or social environment in which he lives. Indeed, it acts to change the character of that relationship, that precarious intrafamilial balance which comes to be formed after the first traumatic impact. When the school period has drawn to a close (the only period of the handicapped

person's life in which there is active help), the entrance into the world of work takes place. This involves a thousand difficulties and the socialization of the disabled person is unsuitable and inadequate. On the other hand, because of a natural physical and psychic development which comes with youth and adolescence, the needs and requirements of the handicapped person grow greatly. His physical powers increase, his intellectual capacities improve, and there is an explosion with regard to his sexuality.

During this phase, the family of the disabled person, more than ever before, should not be left alone. This is because there is a continual state of tension, a daily and even physical weight which can exhaust the energies of somebody who has already given a great deal for years, of somebody who has overcome the torture of doubts and anxieties which have arisen during the first stages of the disabled person's life. Janes, Mazzoldi, and Folgheraiter express all this very well when they declare: " The more the child grows, the more the difference between him and other children becomes apparent. It no longer appears remediable, and the problems and difficulties grow ever greater. They are tackled and faced up to in an ever more uncertain way, and dealt with successfully ever more rarely. The parent, when he has become elderly, worries about being able to guarantee the future of his child who will outlive him, but who is already in many respects " older " than he is. After all, he has very little independence and is left to himself. This is a very sad and difficult phase in the life of a family, and at such a time the family clearly has need of help.

Generally speaking, very little is said nowadays about the socialization of the family. But it is very important because it places the family in the context of other families which have the same problems. In such a way the horizon of the family is expanded and, as has already been said, one realizes with amazement that in this process one learns more from the child than one is able to teach (Blavati). There is a realization that a handicap should be considered as another problem and not as a blow from above, that it is not only a private problem but a social and cultural problem as well. It should be recognized that it is precisely because of this splendid effect produced by love and solidarity that the families, acting through their associations (here in Italy ANFAS is pre-eminent), have managed to make such great steps forward towards a truly civilized solution to the problem of disability.



The world of voluntary work makes a very great contribution to the socialization of the handicapped person and his family. At a recent conference at Florence held on the subject of the New Humanism—a conference which sought to celebrate a current of thought which reached its apex in Florence in the fifteenth century—I declared that the admirable movement of voluntary work should draw upon the spirit of New Humanism. Voluntary workers can and do make a very real contribution to solving the problems of families which have a handicapped member. The voluntary worker acts to heal the narcissistic wound of the family, to reduce the strain of psychophysical care, to reduce the dependence of the disabled person, and to plan a rational program of education in conjunction with the members of the family and the institutions which have a role to play. The world of voluntary help is living proof that society actively accepts the handicapped person. It is much more than a philanthropic exercise—it means solidarity and the achievement of the highest human values. In a certain way it is a kind of adoption.

The environment, in various ways, can become a cause of disability. Modern life styles, of many young people but of many adults as well, are the principal villains of the peace. One of the dramatic features of society—something which is forgotten or only superficially considered by public opinion or by the powers that be—is the way in which there is an ever increasing number of permanently disabled people whose handicap was caused by the work environment or by traffic. On the whole, these are young people who have lost the use of their limbs after irremediable damage caused to their spine (paraplegics and tetraplegics). In Italy alone there are tens of thousands and their num-

bers increase every year: paralysis of the limbs begins during youth or early youth as a result of damage which arrived like a bolt from the blue and led to a major reduction in the quality of life. But the paralysis involved is only one aspect of the clinical picture. Being bed-ridden, these people develop bed sores. Muscular atrophy and incontinence can appear. Infections easily arise. A very serious respiratory deficiency can develop in the case of tetraplegics.

By such routes does the life environment create a new category of handicapped people. And, of course, human progress has radically altered this environment, with both good and bad results—a familiar feature of all forms of human activity! For such people, previously in the very flower of youth, a future of suffering and marginalization stretches out before them.

It is sad to recognize that in our country very little has been done, and very little is being done, for these handicapped people. I would like a strong cry in their favor to arise from this conference. The number of spinal units which are capable of supplying all-round forms of immediate treatment and furnish gradual rehabilitation and re-education with the aim of achieving final re-integration into the family or society can be counted on one hand. As a result of this situation of a lack of spinal units, which does not exist in many other countries, precious hours and days are lost in treating the patient and irreparable damage is caused. It is because of this dramatic situation that there is an increase in those seeking help abroad. Many young people, workers and students, become marginalized from the world of work and study because of the difficulties they have in the use of their bodies (to echo Valli), even though their humanity and dignity remain fully intact.

In the case of disability caused by brain damage, the mind immediately thinks about a category of handicapped people afflicted by damage to the central nervous system—those suffering from multiple sclerosis. Its incidence is very high: in Italy one person every four hours falls victim to this condition. The disease progresses over the years (sometimes for decades) and can lead to a total loss of self-sufficiency. When the support offered by the family is not enough, the people afflicted by this condition are admitted to wards of long-term confinement (when this is possible). They are young adults who live in hospitals for chronic invalids together with elderly people who are also not self-sufficient. No special wards are available for these elderly people. Above all else, there is a lack of provision of any kind of help at home on the part of the community. I am thinking here of something like hospitalization at home, a kind of help which must be truly developed if we are to avoid the hospitals filling up with an infinite number of patients. But this is a question which deals with matters which go far beyond the question of disability.

The environment has another, and always negative, effect upon the life of the handicapped person. I am here referring to the so-called "architectural barriers," which can be seen as being of secondary importance only by those who have a misinformed and superficial vision of the handicapped person They are, in fact, very serious problems and put civilized society in a very bad light.

In recent days the Press has drawn attention to painful episodes of marginalization (we are dealing here with exactly that, unfortunately!) which have occurred because of the persistence of impossible physical barriers. It has been said with a certain crudity but also with marked realism that in order to break down these architectural barriers it is necessary to remove those barriers which are present in men's minds. For many years now the law has decreed the elimination of obstacles in all public and private buildings open to the public. In very recent legislation (Art. 24, par. 7) there is the declaration that buildings which cannot be used by handicapped people are to be deemed uninhabitable and unfit for use. In addition, there are penalties for people who plan and carry out construction and building work without taking into account the requirements of this legislation.

The realities, however, are before our eyes. The obstacles are everywhere and wherever one goes—in homes, offices, streets, the entrances to churches, and wherever there is an entrance to a place used for meetings, culture, or recreation. As long as things remain as they are, social integration for disabled and handicapped people will remain a dream and a utopian vision.

As is well known, handicapped people have special health problems, for example, of a respiratory, neurological, or cardiological character. They regularly need treatment, health care, physiotherapy, and dentistry. Supplementary action and care is needed in addition to the continual requirements that the handicapped person has because he is handicapped—the need to arrange for personal hygiene, food, clothing, being accompanied, and so forth. One revealing example is that of those who are afflicted by the Down Syndrome (Lejeune and collaborators). In Italy alone there are eight thousand Down children under or of the age of fourteen, and twenty-eight thousand Down individuals. Survival up to eight years old is achieved by 75% of the members of this category. 50% survive until the age of forty-seven years old; 25% are still alive at fifty-five; and 5% reach the age of sixty-five (Dagna Bricareli, Perfumi, and Pierluigi).

The serious but variable mental deficit of Down individuals, which is typical of this syndrome, does not mean in the least that a person afflicted by this condition cannot acquire new knowledge and abilities. With the passing of the years they continue to learn, they reach a good level of personal autonomy, they acquire a linguistic level which allows them to communicate with other people, they can have interests and free time activities, and they can be integrated into the work and school environment (Zupi).

With a rational program of rehabilitation, 80% of Down children are able to follow the courses to be found in the elementary and compulsory schools. At the same time the young person with the Down syndrome displays a strong tendency and propensity for independence, and for integration into the world of work (Moretti).

After puberty a new and very serious problem affects the families —the attitude that should be adopted and the choices to be made

in relation to the sexuality of the disabled child. In this field, also, the family feels alone. Indeed, at all levels this question is never spoken about—there is a sort of social censorship of the sexuality of handicapped people. It is a great tabu (Cameroni). In the case of the person who is handicapped in his movements the family tries to inhibit the sexual component of the child in order to protect him. But this overprotection ends up by giving rise to dangerous situations of conflict. In the case of the person who is mentally handicapped,who thus in general is unable to manage his own existence in an independent fashion—something, except for exceptional cases, which does not make him dissimilar with regard to his sexuality—the repression of the sexual drive is even more pronounced, and the family lives in a continual state of fear about the various dangers which could arise. Sexuality, in fact, is not the beginning of independence, as is usually the case. The dependence on the family continues, and the parents act so that the child always remains a child—" sex is not for him " Overprotection in the family environment, marginalization in the social sphere—the handicapped person lives out two contradictory realities (Cottini). Sexual education involves a very high level of responsibility in the case of normal people; it is almost an insuperable problem in the case of handicapped people. " Only when there is a true acceptance of the handicapped person as a person, notwithstanding his diversity, will the question of his sexuality be considered in a balanced way " (Cottini).

The number of handicapped people is very high. There are a whole variety of disabilities of varying levels of handicap and they involve problems of care, rehabilitation, education, schooling, and social and workplace integration, all of which are extremely varied and complicated. We need to recognize that enormous steps have been taken in order to promote the development of handicapped people. Old prejudices have been overcome. It is crystal clear that the old concept that nothing could be done and that marginalization was inevitable must be absolutely rejected. There are innumerable examples of people with serious disabilities who were previously considered hopeless cases but who then went on to achieve a satisfying level of independence and learnt to communicate.

Because of technological advance, which has gone beyond all expectations, people suffering from motor and sensorial disabilities have been able to greatly reduce their deficit. There are indeed extraordinary instruments which allow, for example, a person to use a computer even if he does not have the use of his arms. Instruments also exist which help in feeding people who cannot do this operation themselves, or which allow the disabled person to communicate through ideograms which represent phrases taken from everyday speech. These amount to electronic voices for those who cannot speak. There are even instruments which aid in the preparation of professional training.

In the case of people who are mentally retarded the problems of development and growth are that much greater. In this area the role of the educator is even more important. It is a role that is difficult and which requires great solidarity and great patience. It is for this reason that it must be based upon true and authentic motivation. It also requires a suitable scientific and technical education. The teacher must have a deep knowledge of the developmental processes of the handicapped person—something which must be part of his wider and more general education (Mazzini).

Unfortunately, there is a very great lack of what is needed in this area. This comes as no surprise when the medical training courses do not deal with the handicapped person and his problems. This is all borne out by clinical, morphological, and epidemiological data. Everything is taught in a fragmentary way and there are no references to prevention, to special help, or to social integration. A great advance should be made with regard to these training courses. And it is to be hoped that in this area—perhaps more than in others—so-called " short-degrees " will be established which train suitable people for schools (support teachers), social-educational centers, and courses of professional preparation and orientation.

The education of handicapped people is one of the most modern of today's forms of charity, according to De Seze. The educators of the Center of Urbino are quite right when they say: " At the beginning we thought that we would work for them; now we know how to appreciate the richness of living with them. "

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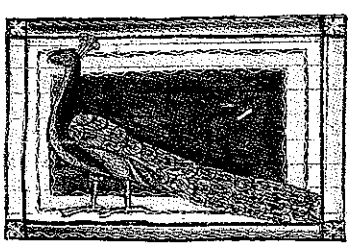

WILLIAM B. SMITH

The Body: Temple of the Spirit

In the single Epistle, First Corinthians, St. Paul asks two questions that link both the theme of this conference and the topic of this paper: " Do you not know that your bodies are the members of Christ? " (*Nescitis quoniam corpora vestra membra Christi sunt?*) (*1 Cor* 6:15) and, " Do you not know that your body is a temple of the Holy Spirit? " (*Nescitis quoniam corpus vestrum templum est Spiritus Sancti?*) (*1 Cor* 6:19).

The answer to both question is " yes " Yes, without qualification! Yes, without invidious discrimination of any kind—every member of the Body of Christ is a Temple of the Holy Spirit. Just as there is neither Jew nor Greek, neither slave nor free, not male and female, there is neither abled nor disabled, " for you are all one in Christ Jesus " (*Gal* 3:28). It is a constant theme of Holy Scripture that God " plays no favorites. "[1]

Thus, every member of Christ is a temple of the Spirit of God. The teaching of the Mystical Body is completely *inclusive* (able and disabled) and in no way exclusive (discriminating, nor even distinguishing beween able and disabled) All are members of Christ's Body and all are temples of the Holy Spirit! The received teaching on the Mystical Body of Christ is all the more necessary to repeat and to expand today, for there still exist selfish hearts that exclude rather than generous hearts that include.

We have been privileged, in recent years, to see the removal of certain walls of separation; the lowering or lessening of well-known curtains (whether " Iron " or " Bamboo ") which, if not completely down, are more splintered than spliced. We have now before our eyes in the East and the West situations in which human solidarity has not been realized—wherein the disabled have not been integrated but continue to be marginalized, even neglected, situations which cannot be blamed on some system, society, structure, or institution that is no longer there. How correctly (and prophetically) did the present Pope, John Paul II outline and predict:

" At the heart of every situation of sin are always to be found sinful people. So true is this that even when such a situation can be changed in its structural and institutional aspects by the force of law, or—as, unfortunately, more often happens—by the law of force, the change in fact proves incomplete, of short duration, and ultimately vain and ineffective—not to say, counterproductive—if the people directly or indirectly responsible for that situation are not converted. "[2]

Previously, the *document* of the Holy See for the International Year of Disabled Persons (1981) made the same point about the need for personal and practical conversion of heart precisely in the context of legislation meant to help and/or advance the disabled:

" Even the best legislation, however, risks having no effect on the social context and not producing

full results if it is not accepted into the personal conscience of the citizens and the collective consciousness of the community "[3]

As above, whatever walls or curtains of separation remain or fall, there remains everywhere the crucial question of attitude, that change of heart realized only in an upright conscience.

Obstacles of a Philosophical and Theological Kind

On October 6, 1984, the International Theological Commission issued and published a series of " Propositions on the Dignity and Rights of the Human Person "[4] In listing some comparisons and suggestions, amid the variety of human conditions, the I.T.C. noted some attitudes and approaches toward human rights that are very pertinent to our understanding of the rights of the disabled.

They noted that in the so-called First World, human rights are loudly proclaimed and many efforts are made to ensure their practical implementation. But when understood in merely a formal way, with inordinate stress on the factor of individual autonomy, such a view of liberty runs the risk of not producing genuine human dignity. In these societies, personal wealth and individual liberty are strongly fostered. Nevertheless, this incentive to " consumerism " sows the seeds of its own selfishness.

In these societies, the sense of higher values is often lost (naturalism); everyone looks only to his own interests (individualism); and the willingness to accept moral norms (limits) even vanishes into a form of practical, material laxism (ITC, n. 3.1.2). The result is that any limits imposed on one's personal liberty (even for the common good or for the maintenance of the rights and liberties of others) are resented. Surely these tendencies towards exaggerated individualism and its baneful effect on common good obligations are not new nor is their observation.[5] While it is not exclusively true of the so-called First World, there is a built-in mentality that can lead to the exploitation of the weak by the more powerful, and the maginalization of the less-able or disabled is a powerful corollary since, after, all, the disabled are dependent, to some degree, in a social situation that prizes individual independence above all else

What the ITC called the Second World they then described as " real Marxism, " wherein constitutions and laws had one way of looking at the human person but another way of acting, so much so that the rights of man were verbally recognized, but their actual meaning was quite different (ITC, 3.1.3).

According to *historical materialism* the human person is not created by God but is simply the result of the evolution of matter. Individual rights are never strictly private but always concessions, kind of an interim moment on the way to the definitive life of the collectivity; good and evil are merely functions fostering or frustrating this historical inevitability; and so the individual conscience does not truly matter but rather the collective conscience as mirrored in the individual.

Our own 20th century has seen examples produced both by exaggerated individualism and exaggerated collectivism that were literally lethal to the disabled and the handicapped. The first was a book co-authored by two eminent professionals, published in Leipzig, in 1920: *Die Freigabe der Vernichtung lebensunwerten Lebens*.[6] The date of publication, 1920, is important because this was the time in Germany of the Weimar Republic, a time of run-away and exaggerated individualism, a time when some professional elites were contemptuous and dismissive of all traditions: medical, legal, and ethical.

The authors were not National Socialist (not yet invented) politicians or ideologues, but rather two distinguished university professors: the jurist, Karl Binding (retired after forty years at the University of Leipzig), and Alfred Hoche, Professor of Psychiatry (University of Freiburg). Binding centered on the medical doctor's legal responsibilities; Hoche argued that killing was compassionate and consistent with medical ethics. Again, this is not a hurried tract nor quick xerox job, but carefully argued in the numbered-paragraph form of the traditional philosophical treatise.

The key to it all is stated clearly in the title: *lebens-unwerten Lebens* —" Life Unworthy of Life "—not only the incurably ill, but large segments of the mentally ill, the feebleminded, and retarded and deformed children. What the au-

thors do is " professionalize " and " medicalize " the notion that there is such a thing as " life unworthy of life. " Once medicalized, they pursue a now new " therapeutic " goal: destroying " life-unworthy-of-life " is a " healing treatment, " a " healing work. "

The problem here is neither politics nor economics; the problem is *ethical*, i.e., the failure of some in the learned professions to keep the oath and ethic of their own professions: medicine, law, and, to some extent, ministry. The ethical collapse begins with the acceptance that there is such a thing as " life-unworthy-of-life " Not only is this a contradiction of the first premise of every medical code (*primum non nocere!*), it is the worst kind of pseudo-humanism, for it simply defines some of the disabled out of the human circle, out of the human race.

Within a generation, within the same country, but later with completely different, indeed opposite, political circumstances (state totalitarianism), medical science takes another lethal turn against the disabled, this time science under dictatorship. To this day, the penetrating analysis of Dr Leo Alexander remains a classic both for its clarity and it cautions.[7] He sums up the correct beginnings of wrong thinking and the crucial part of a wrong attitude:

" Whatever proportions these crimes finally assumed, it became evident to all who investigated them that they had started from small beginnings. The beginnings at first were merely a subtle shift in emphasis in the basic attitude of physicians. It started with the acceptance of the *attitude*, basic in the euthanasia movement, that there is such a thing as a life not worthy to be lived. "

" This attitude in its early stages concerned itself merely with the severely and chronically sick Gradually, the sphere of those to be included in this category was enlarged to encompass the socially unproductive, the ideologically unwanted, the racially unwanted, and finally all non-Aryans. But it is important to realize that the infinitely small wedged-in lever from which this entire trend of mind received its impetus was the *attitude* toward the non-rehabilitable sick ".[8] (emphasis added)

There, in essence, is the crucial and lethal attitudinal shift—a change in attitude toward the *non-rehabilitable* sick. The moment that medicine forgets that *cure* etymologically derives from *care* and deviates from medicine's primary end of healing, there begins an insidious progression of corrosive thinking that by definition is stacked against the disabled and all the chronically ill. Traditionally, where there is no *cure*, we still provide *care*, at least, all ordinary care; any other option is not medicine at all, but a destruction contrary to natural and divine positive law.[9]

Thus, even within our own century, either exaggerated individualism or exaggerated collectivism is quite capable of fostering the pseudo-humanism that can accept, even try to legitimate, the corrupt notion that there is such a thing as " life-not-worthy-of-life, " or reverse the attitude toward the non-rehabilitable sick who are worthy of neither cure nor care These wrong attitudes are, I submit, the most dangerous obstacles to the disabled in any place, at any time

Correct Attitudes

To counter all forms of pseudo-humanism, the Christian must be convinced of the topic title of this conference and this paper, i.e., that the disabled are " members of the Body of Christ " (*1 Cor* 6:15) and " temples of the Holy Spirit " (*1 Cor* 6:19).

The rich and reliable Christian anthropology of Catholic Tradition—so often repeated and insisted upon by Pope John Paul II—must be stated and restated on every occasion, whether convenient or inconvenient (cf. *2 Tim* 4, 2).

Already, in the Document of the Holy See for the International Year of Disabled Persons (1982), the first principle stated is the first principle of all:

" 1. The first principle, which is one that must be stated clearly and firmly, is that the disabled person (whether the disability be the result of a congenital handicap, chronic illness or accident, or from mental or physical deficiency, and whatever the severity of the disability) *is a fully human subject, with the corresponding innate, sacred, and inviolable rights*. This statement is based upon the firm recognition of the fact that a human being possesses a unique dignity and an independent value, from the moment of conception and in every stage of development, whatever his or her physical condition. This principle, which stems from the *upright conscience* of humanity, must be made the inviolable basis of legislation and society "[10]

A convenient and highly concise precis of sound Christian anthropology is found in the Introduction of the Instruction *Donum Vitae* (Feb. 22, 1987) of the Congregation for the Doctrine of the Faith.[11] The Magisterium of the Church offers to human reason the light of Revelation on the doctrine concerning man:

— the life of every human being is to be respected in an absolute way because man is the only creature on earth that God has " wished for himself ";[12]

— the spiritual soul of each man is " immediately created " by God;[13]

— his whole being bears the image of the Creator (*Gn* 1:27);

— human life is sacred because from its beginning it " involves the creative action of God ";[14]

— " at the origin of each human person there is a creative act of God; no man comes into existence by chance; he is always the result of the creative love of God ";[15]

— [human life] remains forever in a special relationship with the Creator, who is its sole end;[16]

— God alone is the Lord of life from its beginning until its end; no one can, in any circumstance, claim for himself the right directly to destroy an innocent human being [17]

This is the *truth* about the human person; and, it is true of all human persons—able, less-able, or disabled. Metaphysically, epistemologically, ethically, every human person (abled or disabled) is by God " wished for himself, " " immediately created, " " in the image of God, " a " creative action of God, " exists " not by chance (but) by creative love of God, " " remains forever, " and God alone is his Lord. These truths about the human person do not admit of more or less; there is and can be no difference in degree nor in kind.

These anthropological truths must be repeated and insisted upon as basic principles before proceeding along any operational lines, whether remedial or progressive. For it is only the truth about man that will refute the distortion that there is such a thing as a life-unworthy-of-life; and it is only the truth that will prevent destructive attitudinal changes against the non-rehabilitable sick

Correcting Attitudes

Again, the Document of the Holy See for the International Year of Disabled Persons (1981) specifies one operational line that needs concrete attention:

" (12) On the other hand, the disabled person must be urged not to be content with being only the subject of rights, accustomed to receiving care and solidarity from other, with a merely passive attitude. He is not only a receiver; he must be helped to be a giver to the full extent of his capabilities. An important and decisive moment in his formation will be reached when he becomes aware of his dignity and worth and recognizes that something is expected from him, and that he, too, can and should contribute to the progress and well-being of his family and community. The idea that he has of himself, should, of course, be realistic, but also positive, allowing him to see himself as a person capable of responsibility, able to exercise his own will and to collaborate with others.[18]

Those of us in the West—particularity, the North Atlantic community—have a stated or unstated bias that is pro-active and anti-passive. The dominance of " independence " in Western thought almost unconsciously puts those who are physically " dependent " at a pronounced disadvantage that fosters isolation, segregation, and neglect instead of integration, normalization, and personalization.[19]

" Independence " (autonomy) is seen and felt as absolutely essential to human dignity. Dignity then highlights the " active " virtues (the one who can do for himself; make his own business; take care of himself and look out for himself). There is a pronounced negativity in our personal and cultural awareness that attaches to passive virtues (meekness, humility, patience, long-suffering, mildness), so much so that not all of the conventional " twelve fruits " of the Holy Spirit are always seen as desirable fruits in consumer culture.[20]

Active virtues arise directly from the moral agent, whereas passive virtues are often responses to what is outside the agent. Curiously, the Western abhorence of dependence only grows as we increasingly practice it—we proclaim our independence but act more dependently on sedatives, technological gadgets, drugs, praise from others, illicit quick-fixes (needles, condoms) all the time. Loud voices proclaim their respect for the nature of the environment; but few voices respect the nature of the human person.

The unconscious but pervasive absolutization of " independence " has grave effects upon the moral consciousness and attitudes that seriously affect the life-death ethic (abortion-infanticide-euthanasia), but especially upon our attitudes toward the disabled. In this sphere, a correct ethic must insist on (cry out for) the incorporation of " dependence " as essential to the notion of human dignity (the principles of *integration, normalization*, and *personalization*[21]).

As a passive virtue, " dependence " refers to the ability to *receive* other persons and their achievements into our lives (e.g., doctors, nurses, therapists, caregivers, etc.). That which is other than myself is freely accepted and, as above, does not preclude the receiver from giving too. Christians should know this instinctively. The Lord Jesus was neither ashamed nor hesitant to proclaim: " Not My will, but Thy will be done " (*Mt* 26:39; *Mk* 14:36; *Lk* 22:42). The vulnerability of " dependence " can lead, as every Christian knows, to new life and new strength.

The communal nature of life—nowhere clearer than in the body metaphor which is the title of this conference: " Now you are Christ's Body, and individually parts of it "; (*Vos autem estis corpus Christi et membra ex parte*) (*1 Co* 12:27).

This means that others become the completion of my incompletion. To be " dependent " is not a moral or social fault; it is merely to acknowledge limits. Indeed, it is those who refuse to acknowledge limits or limitations that cause moral and social faults. To be " dependent " is to be acceptive of the gifts and skills of others, to be acceptive of others in no way lessens anyone's dignity; indeed, it affirms the human solidarity of both giver and receiver.

There is a vital symmetry to both giving and receiving in life. At life's beginning and often at its end, receiving predominates over and even excludes giving. But the value and dignity of human life does not depend *only* on its capacity to *give*. A love that gives and serves (*agape*) has regard for the value of the other independent of particular circumstances. It extends to and embraces all persons—abled and disabled. And if the quality of a society or civilization is to be measured by the respect shown to the weakest of its members,[22] then this regard must especially embrace the helpless and the hopeless; it must especially reach those who think they have no value in their own eyes and seemingly none for society.

Such *agape* love, a love that gives and serves, can be demanding and sacrificial; just as it can be easily destroyed. In the giver, it demands unlimited caring; in the receiver, it demands resolute trust.

This Love that gives-and-serves precludes the possiblity that there is such a thing as life-unworthy-of-life; just as the same Love that gives-and-serves is the only real antidote to injurious attitudes to the non-rehabilitable sick.

Fortunately, this *agape* love that gives and serves is not a foreign element nor an alien import; it is the life-blood (*gratia*) of the Mystical Body of Christ. It need only be shared to be increased: " ... your surplus at the present time should supply their needs, so that their surplus might also supply your needs, that there may be equality " (*2 Cor* 8:14). So that there may be a certain equality or economy of love. This is not only possible, but demanded of those who answer " yes " to the theme of this conference and the topic of this paper:

" Do you not know that your bodies are members of Christ? " (*1 Cor* 6:15).

" Do you not know that your body is a temple of the Holy Spirit? " (*1 Cor* 6:19).

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[1] Cf *Acts* 10,34 " non est personarum acceptor Deus "; cf also *Rms* 2.11; *Gal* 2.6; *Eph* 6,9.

[2] Pope John Paul II, *Reconciliatio et paenitentia* (dec 2, 1984) n 16 (*AAS* 77 1985 p 217).

[3] *Document* of the *Holy See* for the " International Year of Disabled Persons " (March 4, 1981) n 15 (Boston: St. Paul Eds 1981), p 15. For *Document* also cf *Origins* 10:47 (5/7/81) 747-750.

[4] I.T.C., in *Gregorianum* v. 66:1 (1985) pp. 5-23; Eng trans Wash, DC: U.S.C.C. PN. 997 1986 17 pp.

[5] Cf. Alexis de Tocqueville, *De la Democratie en Amérique*, o, G.W. Pierson; D.C. Lunt, *Tocqueville in America* (1831-1832) (NY: Doubleday-Anchor 1959) 506 pp.

[6] K. Binding, A. Hochl, *Die Freigabe der Vernichtung lebens-unwerten Lebens Ihr Mass und ihre Form* (Leipzig: F. Meiner, 1920). For background and influence, cf R. J. Lifton, *The Nazi Doctors* chpt 2. (NY: Basic Books Inc. 1986) pp. 45-79.

[7] L. Alexander, M.D. « Medical Science Under Dictatorship », *New England Journal of Medicine* v. 241 (1949) 39-47. It is no less than severe irony that while Dr. Alexander praises the glorious resistance of the physicians of the Netherlands (1941-1942) to the Nazi euthanasia program, some physicians in the Netherlands today do voluntarily what none of their predecessors in medicine would do nor cooperate with under oppressive occupation.

[8] *Ibid*.

[9] One continuing calumny of the 20th century is that this systematic, state-sponsored destruction of the psychically and physically damaged was passed over with complete silence. This is simply false; cf *DS* 3790; Decree of the Holy Office (dec 2; 1940): " De directa insontium iussu auctoritatis publicae " *Quaesitum* Num licitum sit, ex mandato auctoritatis publicae, directe occidere eos, qui, quamvis nullum crimen morte dignum commiserint tamen ob defectus psychicos vel physicos nationi prodesse iam non valent eamque potius gravare eiusque vigori ac robori obstare censentur? *Resp*. Negative cum sit iuri naturali ac divino positivo contrarium (*AAS* 32 [1940] 553-554).

This was noted in at least one U.S. publication; cf *New Republic*, v. 104 (1941) p. 627; a publication with no known sympathies toward the Vatican.

[10] Holy See, " Document for Year of Disabled Persons " (1981), *op. cit.*, I. 1.

[11] CDF *Donum vitae* (feb. 22, 1987), Intro, n. 5; (*AAS* 80 [1988] 76-77).

[12] Vat. II, *Gaudium et spes*, n. 24.

[13] Pius XII, *Humani generis*: *AAS* 53 (1950) 575; Paul VI, *Professio Fidei*: *AAS* 60 (1968) 436.

[14] Ioannes XXIII, *Mater et Magistra*: *AAS* 53 (1961) 447.

[15] Ioannes Paulus II (17 Sept 1983), *Insegnamenti di Giovanni Paolo II*, VI, 2 (1983) 562; trans. *L'Osservatore Romano* (english ed wk) 41/804 (oct 10, 1983) n 1, p 7.

[16] *Gaudium et spes*, n. 24.

[17] Pius XII (12 nov. 1944): *Discorsi e Radiomessaggi*, VI (1944-1945) 191-192.

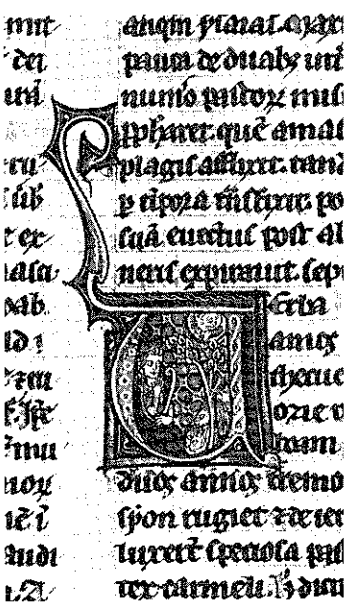
[18] Document Holy See (1981) *op. cit.*, II. 12.

[19] *Ibid.*, I, 4.

[20] The tendency to disparage passive virtues, or at least, separate them from the active virtues was a regrettable tendency in the judgment of Pope Leo XIII; cf. Leo XII, *Testem benevolentiae* (22 gen 1899): *ASS* 31 (1899) 470-479.

[21] Document of Holy See (1981) *op. cit.*, I. 4.

[22] *Ibid*., I. 3.



ALEXANDER NICOLAIEVICH KONOVALOV

Deep-Seated Tumors and Quality of Life

It is a great honor for me to take part in this conference dedicated to such a noble aim as help to disabled people, and especially at such a Conference that has attracted so many illustrious scientists of the world.

A physician of any specialization deals with patients who may become temporary or permanent invalids. By his actions, skills, and talent he helps the suffering people, saves them from disability, if possible.

Any disability that restricts human activity is a hard burden, but it is more tragic when it is caused by brain lesion

Practically all the diseases a neurosurgeon deals with are dangerous and often result in death or disability These illnesses are one of the most frequent causes of mortality and disability of the population. Here I mean such diseases as stroke, rupture of arterial and arteriovenous aneurysms, brain tumors, hydrocephalus, epilepsy, and others.

I want to illustrate that with some data from United States statistics, which are very similar to those in the former Soviet Union.

Every year about a half-millions of head-injured patients are hospitalized; 250,000-500,000 are invalids after spinal injury; about 2 million people survived stroke; approximately the same number of patients with epilepsy; brain tumors are not so common, but without neurosurgical help practically all these patients have total prognosis. Other serious illnesses such as hydrocephalus, malformations are common and result in severe disability. In the light of the problems that are being discussed at this conference I would like to draw your attention to the most important common features of these diseases.

1. Invalidity caused by brain lesion differs from disability that occurs due to other diseases. Brain damage often causes not only physical defects such as motor dysfunction, blindness, loss of hearing, and others but also serious mental disturbances which dramatically complicate compensation of the disturbed functions and the patient's adaptation to his defect;

2. Surgery, which is a very efficient method of treatment of some of the above-mentioned illness, is at the same time difficult, risky, and in itself can be the cause of disability

Often a neurosurgeon faces the dilemma—to save a patient's life at the cost of severe losses, inevitable disability, or to give up the operation, thus leaving the disease to its own course. It is a difficult and agonizing question—what is more humane: to save the life of a person with a changed physical status and deprived of the basic elements that determine one's personality—(intellect), or to prefer a short but worthy human life? This question arises when a neurosurgeon removes a blood clot from the brain damaged by haemorrhage and when he makes a desperate attempt to save the life of a patient with a brain crushed as a result of an accident, or when he removes the tumor affecting vitally important centers.

3. Success in the treatment of more serious brain lesions depends on our knowledge of the brain's reaction to its damage and the nervous system's capacity to compensate for these lesions. It helps to predict postoperative complications and prevent them.

The capacity of the nervous system for restoring the impaired functions is indeed great. That is why skillful and timely rehabilitation is of extreme importance, as it permits help for even very handicapped patients and brings them back to normal or useful life.

4. And lastly, I would like to draw your attention to one more significant aspect: many patients who became disabled as a result of severe brain lesion still need due attention a society. Because of uncertain or fatal prognosis of illness, they are often treated like the doomed, through many of them can be free from repeated threat of disease for many years.

All these problems are extremely acute, especially pronounced in patients with brain tumors and mostly with tumors affecting deep-seated, vitally important structures of the brain.

On the basis of the above-mentioned facts I would like to highlight the problems of treatment and disability of patients with these tumours.

Neurosurgery has made great advances in treating different tumors—with early diagnosis many benign tumors can be cured. But still, for deep-seated tumors, affecting the brain stem and diencephalic structures, prognosis for life and

prevention of the inevitable disability is unfavorable.

The Burdeko Neurosurgical Institute is the center where thousands of patients with brain tumors, vascular lesions, and severe head injuries undergo treatment and, traditionally, here there is a concentration of patients with lesions that are more complicated for treatment. Among them deep-seated tumors have constituted an important part. Here I would like briefly to discuss my personal experience in the radical removal of about 1200 diencephalic and brain stem tumors.

Tumors of the diencephalic region are mostly dysembrionic ones —the so-called craniopharyngiomas—and primary gliomas.

Modern diagnostic methods, first of all, such as MRI and CT, permit us not only to visualize these tumors but to find out their relations to the brain structures

Among them there are realy giant tumors which cause very severe brain damage.

The main syndromes caused by diencephalic tumors are well-known: progressive decrease of vision and blindness; endocrine disturbances; intracranial hypertension and hydrocephalus, decrease of activity up to deep disability.

More dangerous manifestations of brain stem tumors inolve disturbance of vital functions such as breathing, swallowing, blood circulation

The experience gained shows that quite a large number of the abovementioned tumors could be successfully removed. Doubtless, this surgery is still risky; the number of serious complications is high; the mortality rate in the group of the most serious cases reaches 20%. But it is necessary to consider that without surgery, practically all of these patients have been sentenced to death. There are some conditions which make surgical removal of these tumors possible. They concern precise diagnosis of these tumors relations with the brain, which now is possible due to modern precise methods such as CT and MRI.

Brain Protection During Operations

Operations on deep-seated tumors constitute severe trauma that can take away the patient's life. Interventions on structures that regulate all the most significant functions of the organism demand brain protection from additional damage and keeping the vital functions of the organism normal under extreme conditions.

Surgical Techniques

Modern microsurgical techniques make it possible to penetrate into the deepest structures of the brain and remove tumors affecting them. With the help of the microscope even tiny cerebral structures can be preserved.

As these tumors are far from the surface of the brain, selection of the most appropriate approaches is of great importance. For example, many diencephalic tumors, penetrating into the third ventricle, can be reached by dissecting the corpus callosum, when the tumor is completely removed and the base of the skull and basilar artery are exposed. To remove brain stem tumors it is quite often necessary to make incisions in these vitally important structures.

Even giant focal tumors of the brain stem can be successfully removed.

About 60% of patients improve after tumor removal The number of poor results is still high, but one should remember that without surgical help all these patients are doomed.

Removal of diencephalic and brain stem tumors presents many problems—one of the most important is preservation of brain vessels. Even damage to tiny arterial branches supplying this region of the brain may result in serious complications and even a patient's death.

Quite often the most important arteries, such as the carotid artery and its branches, can be included in the tumor and hours of meticulous preparation under the microscope are necessary to separate and to preserve these vessels.

Intensive Care

Removal of brain stem tumors may result in dramatic changes in

blood circulation and breathing disturbances. Artificial breathing is life saving in some of these patients. Prolonged mechanical ventilation is necessary before this damaged function will recover.

I remember a boy with a tumour of the medulla ablongata and pons who was accepted in the Institute in a very severe condition; the tumor was successfully removed and the child was practically sound for two years. Because of recurrence, he was operated on for the second time two years later. This time the tumor destroyed vital brain stem centers and after surgery the boy's breathing was too weak and he needed artificial ventilation for more than a year. Mentally, the boy was bright and while in hospital became a good artist.

Another serious complication may happen in the acute postoperative period: changes in water —electrolyte balance, disturbances of thermoregulations, epileptic fits, and others which require timely correction. The causes of some of these complications have yet to be established. For example, my colleagues at the Institute found out that damage to diencephalic structures often results in widespread disturbances of cerebral circulation with multiple ischemic lesions in different structures of the brain, causing patients' disability and mortality.

Rehabilitation

As was mentioned before, rehabilitation aimed at the maximum utilization of brain resources helps to decrease disability of patients with damage to the deep brain structures. It must be started in the early postoperative period and prolonged during further stages of treatment.

In removing tumors in deep structures of the brain, a neurosurgeon should first aim at saving or prolonging a patient's life. At the same time, he must protect a patient from such horrible consequences as blindness, endocrine deficiency, mental degradation, etc. I shall briefly, dwell on these problems.

Prevention of Blindness

Tumors that develop in the third ventricle region very often affect optic nerves and cause blindness. As a rule, these tumors occur in children and reach giant volumes.

Only in recent years have surgeons started to consider removal of these tumors as justified.

In conducting operations on such patients, we naturally were ready to face the problem of residual vision loss. However, the experience gained lately shows that radical tumor removal with observance of microsurgical principles does not usually cause substantial vision impairment, and in some cases improvement was evident.

Endocrine Disturbances

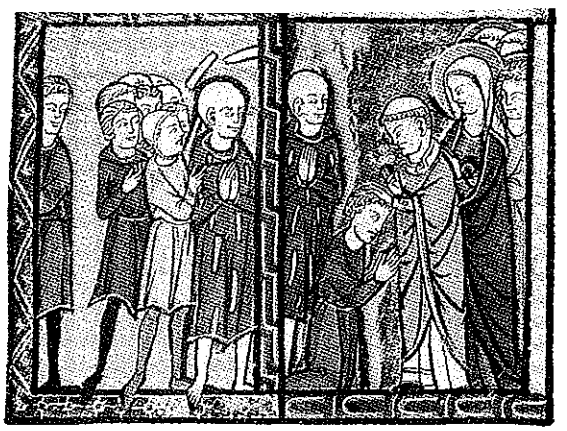
As a rule, they exist before surgery and remain after it. Even the most delicate operation is accompanied by the aggravation of these disturbances.

With the help of special substitution treatment many disturbances can be corrected.

Speaking about endocrine disturbances, I would like to dwell on diabetes insipidus, that is manifested in a dramatic water metabolism disorder. Patients lose dozens litres of water and must drink water constantly if substitution hormonal therapy is not used. The reason for this complication is damage to the pituitary stalk. In this connection a neurosurgeon faces a complicated task—to reveal and, if he manages it, to preserve these tiny structures, that can be included in the tumor and be destroyed by it. The experience we have gained helps us to solve this difficult task.

Prevention of Liquorocirculation Disturbance and Hydrocephalus

Tumors of median localization, especially, located in the third ventricle region, block CSF pathways from internal brain chambers. They cause enlargement of ventricles, increase of intracranial pressure, and brain atrophy. Sometimes there is only a thin plate of brain matter left. This is a dangerous complication that can result in serious mental disability. This complication can be obviated by so-called shunting operations, thus creating new pathways of liquor outflow from brain



ventricles. But, naturally, it is preferable to remove the tumor itself, if possible, in order to re-establish circulation of cerebrospinal fluid. Such operations should be conducted when the hydrocephalus has not reached its critical volume. Otherwise, tumor removal can become the reason for such complications as brain collapse, haemorrhage, etc

Preservation of Mental Capacity

Often these tumors in their development cause medial structure lesions that determine vitality, life tonus, adequate emotional reactions, memory.

Special attention shoud be paid to memory, that can be damaged as a result of the approach to deep-seated tumors.

When performing removal of tumors, we often use corpus callosum dissection and splitting fornix. These operations do not usually cause appearance or aggravation of memory disturbances But this problem exists Several years ago I operated on a young woman—a student—with large tumors of the third ventricle. I was satisfied that I had succeded in radical tumor removal and saved this girl's life, and at the same time I was terribly distressed, as after surgery she developed very serious memory disturbance: she fogot practically all her previous life and was not able to recollect everyday events for a long period of time. She had not returned to the Institute, and I was happily surprised when I met her five years after surgery: she was practically normal: her memory was not brilliant, but quite useful for everyday life.

It should be mentioned that memory deficits on current or past events represent a rather frequent syndrome with different brain lesions, especially in craniocerebral trauma and vascular diseases.

Elimination of these defects or rather their compensation is very difficult; commonly used methods are not known. We have some positive experience in re-establishing memory of patients who suffered from craniocerebral trauma. Nevertheless, I would especially stress that disability caused by memory defects is a difficult and practically unstudied problem.

Prevention of Epileptic Attacks

It is known that epilepsy may be a genuine substantive disease or a syndrome of brain damage, for example, brain tumors. It is accompanied by loss of working capacity, stable disability of patients, and often by their complete helplessness.

Prevention of epileptic attacks that can be the result of surgical intervention on the brain is a serious problem that must be settled by neurosurgeons who perform removal of deep-seated tumors.

Our experience shows that the choice of the approach to the tumor is of a great importance. That is why we prefer approaches through corpus callosum rather than approaches through the cortical fields which can result in postoperative epilepsy

I have highlighted only some illustrations of the consequences after deep-seated tumor removal. This complicated field of neurosurgery helps us to understand what dangerous complications that incapacitate patients can be observed in medial brain structure damage.

In conclusion, I want to stress that modern neurosurgery may efficiently help millions of patients with different serious illnesses and damage to the nervous system and prevent or diminish disabilities caused by this illness

Rendering assistance to these disabled people is not only a medical problem, but a social one.

Unfortunately, such handicapped people are very often not the concern of society, that is quite indifferent towards such people and does not help them to find their place in life, to overcome severe consequences of the disease. Many of these disabled are treated like the doomed.

I, as a physician who understands the complexity of this problem—quite often the tragedy of such patients—appeal to you to pay special attention to the fate of people with brain lesions

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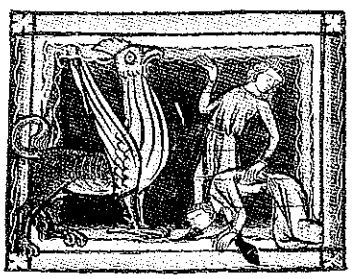


JOHN R. BRECHTL

Disability and AIDS

The human immunodeficiency virus (HIV) epidemic is appropriately designated a pandemic. Globally, HIV infections have been documented in all countries.[1] The pandemic is accelerating and characterized by further geographic spread rather than stabilization. By 1995 an additional 5.7 million adults and 1.2 million children will become infected with HIV.[2] Likewise, there will be a rapid increase in the number of people developing AIDS. During 1992-95, they will number 3.8 million—exceeding the numbers who developed the disease during the entire history of the pandemic until now.[2,3]

In the United States, recent data suggest a modest increase in the median time of survival following a diagnosis of AIDS although the prognosis remains poor.[4] Increased survival reflects access to adequate medical treatment and creates a population which manifests certain clinical features of AIDS not heretofore as prevalent These clinical features often result in disabling conditions that require treatment and supportive medical care.

It is the contention of this paper that government and the medical profession are obligated to provide the opportunity of adequate medical care to all persons disabled by AIDS regardless of disability or stage of disease In doing so, it is required that they: 1) counter any emerging trends that disvalue some lives or promote the right-to-die on the basis of a terminal diagnosis, 2) minimize any stigma assigned to persons with disabilities and AIDS that would limit health care provision or access, and 3) appeal to a more egalitarian, rather than utilitarian, principle of justice when determining health care resource allocation.

First, a brief description of an AIDS Discrete Unit model program that attempts to adhere to this obligation and its requirements is provided.

AIDS Discrete Unit Model

In 1989, Terence Cardinal Cooke Health Care Center (TCC), a New York Archdiocese facility affiliated with New York Medical College, opened a 44-bed inpatient AIDS Discrete Unit (ADU) TCC is a 600-bed facility that contains a large skilled nursing facility (SNF), geriatric population, and a program for severely developmentally disabled children. The ADU was the first such SNF unit in New York State and has subsequently grown to its present 156-bed capacity, the largest in the U.S It is staffed by full-time physicians. Acute medical care and hospice-like care is provided to patients. The provision of acute medical care is atypical of a traditional SNF.

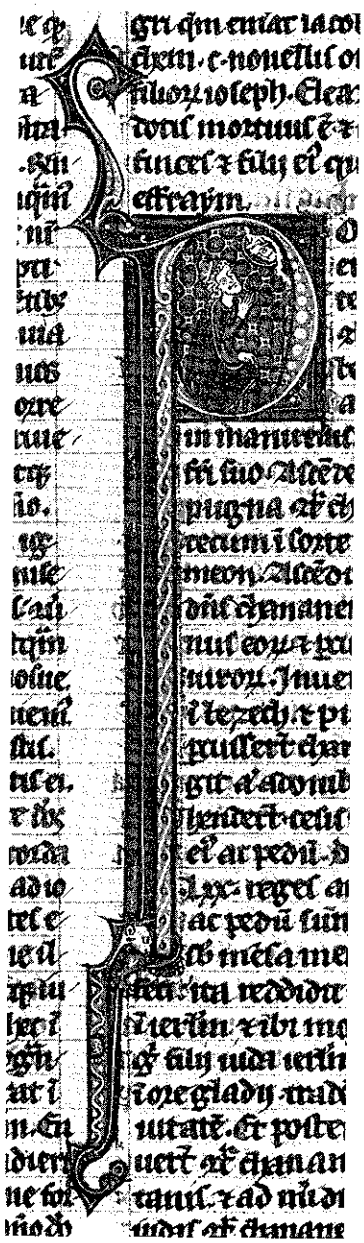
Since its opening in 1989, nearly 800 patients with AIDS (PWA's) have been admitted. Most are in the late stage of the disease; others are in an earlier stage but significantly disabled. They are either too disabled to be discharged to the community or are, in fact, homeless.

Most patients are minority Afro-American or Hispanic. The mean age is 39. The predominant risk factor for HIV infection is intravenous drug use (68%), followed by male homosexual activity (26%). The length-of-stay (LOS) on the ADU is a mean of 110 days. However, there is a bimodal distribution in that 42% of patients have a LOS of less than 30 days (usually ending in death), while 48% have a LOS in excess of 90 days. Within this latter group there are patients (24%) who are residents for a minimum of six months. Some of these are treated for long periods (>1 year) and are subsequently discharged home to the community.

Treatment interventions are initiated, such as intravenous therapy or blood transfusions, unless patients are considered terminally ill in the sense of imminently dying and/or treatment is unlikely to reverse the new disease process. Full disclosure of clinical condition and probability of reversibility are made to patients, families, and/or surrogates regarding these treatment decisions. The Do-Not-Resuscitate (DNR) status does not alone determine the initiation or withholding of treatment, nor does the mere diagnosis of late-stage AIDS.

Clearly, these patients have physical disabilities. However, they also have psycho-emotional, societal, and spiritual disabilities. Psychological disability is frequently related to the direct organic effects of HIV and/or longtime illicit drug use, underlying personality and adjustment disorders, or depression. Societal disability relates to homelessness and estrangement. In a recent report by the U.S. National Commission on AIDS, it is estimated that up to half of all Americans with AIDS are either homeless or about to become so, and at least 15% of people living on the streets are HIV infected. Most patients on the ADU would otherwise be homeless.[5]

Likewise, there is spiritual disability manifest as desolation. Yet



most patients become re-related with their God and reach peaceful reconciliation. It is a quiet process but evident to those who observe it. Given the time and opportunity, they reach peace in anticipation of the inevitable outcome—death due to AIDS.

Regarding AIDS and disability, it is of interest and encouraging that the Americans with Disabilities Act of 1991 (ADA) covers both PWA's and those HIV-infected who are asymptomatic. Disability is defined broadly to include all physical and mental conditions that significantly limit a person's major life activities. The ADA impacts on the health care industry and physicians by prohibiting discrimination on the grounds of a person's disability.[6]

The projection regarding future numbers of cases of AIDS and evidence that overall survival is increasing adds further demands on health care systems to provide medical care and support to these patients. The program at TCC has proved successful in providing these services and can serve as a model to others.

The key medical elements of such a program are the ability to provide the spectrum of acute to hospice-like care; recognition of the fact that this patient population cannot be categorically defined as end-stage AIDS, but, rather there are some patients simply disabled by AIDS with reasonable or unexpected length of survival, some with restorative and discharge potential; and medical care intervention decisions are invidualized to patients' needs based on clinical condition rather than merely the DNR status or the terminal diagnosis of AIDS.

Right-to-Die/Quality-of-Life

The TCC program runs countercurrent to certain emerging movements in the United States that have gained momentum in the public and political arenas. These movements claim a person's right-to-die based on quality-of-life determinations. Patients with the terminal diagnosis of AIDS become an easy focus for exercising this right.

The right-to-die movement would argue that, based upon the moral principle of respect for autonomy, or self-determination, a person with a terminal diagnosis who is not necessarily terminally ill has the right to choose suicide by refusal of treatment, and this choice must be respected by others. The more radical argument contends that the option for suicide can be actively assisted by physicians. In November 1991, a Washington state voter referendum (Initiative 119) that called for physician-assisted suicide for the terminally ill was narrowly defeated. Had the referendum passed, Washington would have become the only jurisdiction worldwide with legalized euthanasia.[7] This movement has received significant media coverage due to the lay publication of the Hemlock Society, which provides clear-cut methodologies for unassisted suicide.[8]

In its moderate form, the appeal to right-to-die and respect for autonomy is manifest in the Patient Self-Determination Act, which took effect in December 1991.[9] This law was designed to increase patient involvement in decisions regarding life-sustaining treatment by assuring that advance directives are available to physicians.[10] The law facilitates the decision-making process regarding incompetent patients, the terminally ill, or imminently dying, and some patients on life support systems; however, it is also a vehicle to exercise the right-to-die by precluding all treatment regardless of clinical circumstance. In this sense suicide by omission or passive euthanasia can become an option for an advance directive.

The moral principle of respect for autonomy is sound. However, when this principle is expanded to justify or facilitate suicide and euthanasia for persons with a broad range of medical conditions, the principle is wrongly applied. While suicide may be an autonomous act opted by a competent person with a terminal diagnosis, it does not follow that the principle of respect for autonomy justifies the act merely because it is autonomous. Nor is right-to-die applicable merely because of the autonomy of the act. It appears that autonomy itself is the appeal, rather than respect for it,

that attempts, to justify right-to-die.

Intrinsic to the right-to-die notion is determination of quality-of-life. While the rationality of suicide is debated generally because of psychiatric and emotional disorders that affect judgment,[11] the person deciding for suicide has concluded that life is not worth living. In the context of right-to-die in medical conditions, this conclusion is determined by a patient independently or is influenced by third parties close to the situation. Alone, or in concert with these influences, a patient may, it is argued, exercise the right-to-die by refusing all medical therapy.

Criteria to determine quality-of-life in general are at best vague. In modern countries, where material and personal comfort appear to be the standard, determination relies heavily on the extent of pain and suffering, both physical and emotional. While benefit versus burden of treatment are considered, the emphasis is on burden. Relation roles with family and society are also weighed and considered either contributory or burdensome.

Because of the difficulty in determining quality-of-life, the tendency is to designate poor quality on the basis of diagnoses and projected survival as much as the actyal clinical conditions of patients. Such a categorical approach is easier. Thus, a life can be determined futile, i.e. not worth living, for a patient with a terminal diagnosis only (AIDS) or whose projected survival does not likely exceed an arbitrary limit.

Categorical determination of quality-of-life loses legitimacy when applied to such circumstances. Utilized to categorize patients as living futile lives, it promotes right-to-die. In doing so, it becomes an accessory on the road that predictably leads to euthanasia, and an already stigmatized population becomes more vulnerable. Legitimation of its application, buffered by emphasis on right-to-die, easily leads to acts that are morally objectionable. Once this line is crossed, it becomes nearly impossible to draw back again to proclude such unacceptable practices in society.[12]

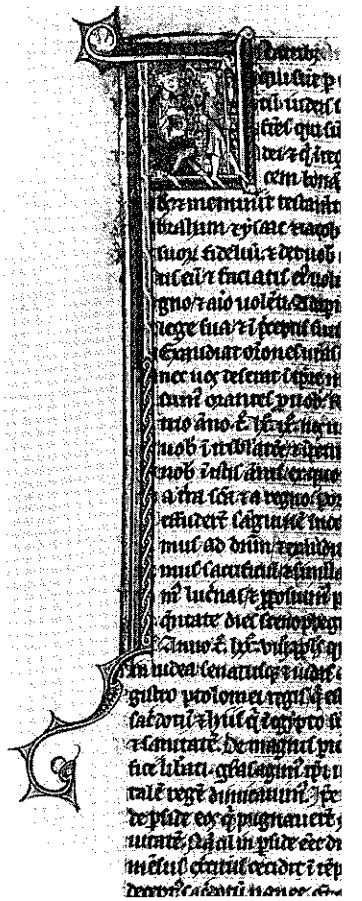
Stigma

There is stigma associated with disability and AIDS. It is based on objective or subjective value judgments that reach negative, or disvalued, conclusions about the individual. The stigma of physical disability is based on an objective value judgment that is quantified to a degree by type and severity of disability. The stigma of a disability inherited or acquired through no responsible act by the person differs in relation to the subjective stigma associated with high risk behavior. Innocent victims carry the stigma of disease but not behavior.

The stigma of HIV infection or AIDS influences societal reactions. Apart from fear of contagion is the stigma assigned to high-risk behavior groups—intravenous drug users and homosexuals. It is a fact that their behavior results in HIV infection; thus, it is argued by some that they are personally and fully responsible for acquisition of HIV infection and associated morbidity. The argument could conclude that they have forfeited their right to health care at the same level as others, i.e., the innocent victims.

It is not certain, however, that full responsibility can be categorically assigned to this population. While high-risk acts of themeselves cannot be condoned as morally good or neutral, nor exempted from causal acquisition of HIV infection, it does not follow that the actors are fully responsible for all consequences. Given full awareness, their only rational conclusion would be abstinence from risky behavior. However, it can be argued that high-risk behavior is not based on full awareness of risks and consequences, nor are they voluntarily accepted. Contributing social and psychological conditions alter degrees of personal responsibility.[13]

The condition of drug addiction or drive for homosexual activity affects behavioral decision-making by the self-perception that abstinence is either impossible or achieved with severe difficulty. This perception, when coupled with incomplete awareness of risk of HIV infection or its consequences, results in continued, habitual high-risk behavior. A large portion of



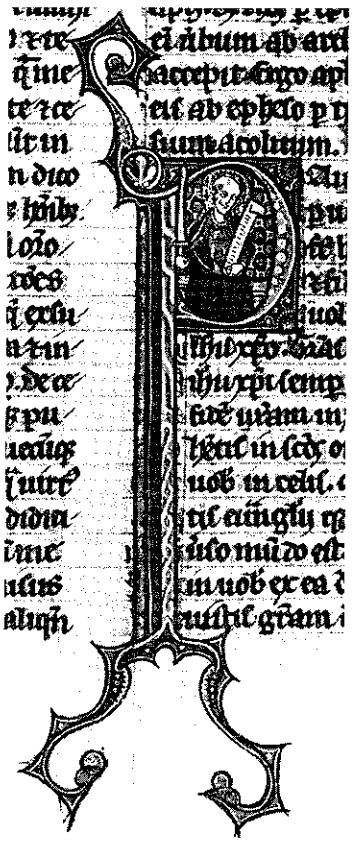
this population is also victim to a poor social lottery outcome; that is, it is designated by birth to the lower spectrum of society relating to family, neighborhood, and education, where high-risk behavior is more commonplace

Reaction to the stigma of AIDS varies in society but is sharply exemplified by the medical profession. The American Medical Association (AMA) stated in 1988 that: "A physician may not ethically refuse to treat a patient whose condition is within the physician's current realm of competence solely because the patient is seropositive for HIV."[14] Yet, while 68% of polled primary care physicians believe they have a responsibility to treat AIDS patients, half (50%) indicate they would not if given a choice.[15] Despite public policy statements by the profession, there are clearly negative attitudinal responses to the stigma of AIDS that are evidenced by unwillingness to treat these patients.

Any appeal to obligation-to-treat by physicians during epidemic on the basis of tradition alone, however, is not well substantiated. Historically, while some physicians have heroically treated infected patients with considerable risk to themselves, others have denied treatment and, in fact, fled epidemic areas.[16] Neither can obligation-to-treat be argued on the basis of patients' claims of rights to health care nor the patient-physician contractual relationship. The claim of right to health care is one against society, not individual physicians; and the patient-physician contract sets legal standards of care received, but allows physicians to refuse establishing such relationships.[17]

Nor is a physician obligated to encounter excessive risk in treating any patient. However, the risk of contagion from an HIV-infected patient is small.[18]

There is no justification to deny treatment on the basis of occupational risk. Nor is a physician obligated to deny treatment on the basis of occupational risk. Nor is a physician obligated to provid futile treatments; however, there is the duty to provide care. Denial of treatment based on a value judgment that determines a patient's situation to be futile on the basis of HIV-positivity or AIDS alone is unjustifiable.



Instead, the obligation to treat PWA's must appeal to the moral or virtue-based ethic inherent to the profession that requires service to those in need. A virtue-based ethic, when used in reference to normative ethical principles, can imply voluntary, not obligatory, behavior. An individual is not required to be virtuous to be a good citizen, even though such behavior is recognized as good. When applied to the medical profession, however, there is no option for virtue; it has already been attested to by physicians and the profession through its accepted responsibility to treat those in need in society. It is this moral ethic of the profession that applies to all physicians. It precludes denial of treatment to any patients based on discrimination evoked from stigma. Such discrimination is intolerable, and the appropriate sectors of the profession, rightfully, must be outspoken advocates of those in need. This can prevent further stigmatization of patients with HIV infection and AIDS whose access to health care is threatened by discriminatory neglect.

Health Care Rationing

In a just society attempts are made to distribute limited resources in a fair manner. This becomes a challenge under conditions of scarse resources and competition for those resources.[19]

Distribution is accomplished by macroallocation, whereby government determines the types of services provided, and microallocation, or rationing, which determines who will receive the services. Rationing decisions to limit certain services involve judgments of social utility which may distinguish between greater or lesser social worth of lives. In contrast, medical utility traditionally aims for one standard of care for all based on equal social value of lives.[20] The stigma of certain groups, i.e. persons with AIDS, compounded by the emerging emphasis on right-to-die and quality-of-life, can easily impact social utility judgments.

In 1991, the Oregon Department of Human Resources submitted to the U S government a proposal for the state's Medicaid program.[21] The proposed plan's intent was to extend basic health care benefits to more people by limiting the number of services rendered. The plan listed 709 health services and ranked them in terms of benefit to the overall population. Basic health was defined as " a floor beneath which no person should fall "—a definition chosen " from a societal perspective rather than the individual's perspective. " The plan proposed Medicaid payment for services rendered from No. 1 through No. 587.[22]

The plan relies heavily on categorization by diagnosis that does not reflect variation of severity of illness among patients with the same diagnosis. Coexisting conditions likewise are not considered.[22] The plan likewise relies on arbitrary projections of survival for patients with terminal diagnoses. Patients with AIDS with a projected survival of six months or less would not qualify for treatment other than hospice care. The plan exempts certain groups, like the blind and disabled, until 1993, when they would become subject to the same rationing.

In August 1992, the Bush Administration rejected the Oregon plan. It cited concerns about compliance with the 1991 Americans with Disabilities Act, the rigid prioritization system that disregarded a vast variety of clinical conditions, the focused rationing of services to the poor and women on Medicaid, and the potential for more stringent rationing if resources become more limited.[23]

It is not possible to determine the area of influence in regard to stigmas, but it is clear that an already stigmatized population is seen to be the object of rationing: the poor, the handicapped, AIDS victims. It is also evident that such a plan, for utilitarian social judgment, concludes that from a societal standpoint, some lives are less valid than others. It is not certain whether these individuals yield their right to the common standards of health care to which they are accustomed; such a plan rather seems to render this right inoperative for them.

It is regarded as mandatory to determine the allotment of health-care resources in accordance with the principle of justice. The Oregon plan simplifies an approach to allotment based on a utilitarian theory of justice which has been dominant in the United States. While the utilitarian approach to allotment is capable of achieving just results, it is snagged by its dependence on the principle of utility as the only absolute one and may, therefore, produce un just results. Similarly, since utilitariansism takes into account moral norms only in the measure of their consequences or of the moral life as the logical grounding of a means towards an end, it may thus arrive at conclusions which are unacceptable from a moral standpoint. A plan offering the benefits of health care to many people—that is, to a greater number of people—may seem to be based exclusively on objectivity and have positive aims. But, in spite of its meritorious finality, such a plan becomes unjust when it imposes —as a means to an end—limits upon the services to some people. It becomes unjust and immoral when it attributes to certain lives a value inferior to that of others by determining the quality of life and also stigmatizes certain groups in society, like the poor, the handicapped, and AIDS victims.

There is no perfect theory of justice. But egalitarian theories generally contrast with utilitarianism. Rather than reduce a person to his social role in terms of contribution, they maintain that equality is a fundamental right. For this reason we should, to a certain extent, provide people with equal opportunity and distribution of means and services—e.g., health care.

A more egalitarian approach to health care allocation could not arrive at a plan like that devised in Oregon. Rather, based on the principle of equality, it would allocate services based on need, taking into consideration individual circumstances. Likewise, it would be careful to prevent any value judgments of quality-of-life that determine some lives of lesser value than others—this would contradict its basic principle. Last, it would attempt to minimize any stigma attached to certain groups in need for which resources are allocated.

In conclusion, a stronger appeal to an egalitarian mode of justice, preferably one reflecting the Judeo-Christian tradition of justice that embraces faith doctrines of God, creation, and stewardship, or, at the very least, one that compels the secularist to accept equality on basic premises that reach beyond reasons alone,[26] is necessary to rightly address public policy regarding the disabled or PWA's. As a physician caring directly for these patients and one who believes in the transcendental dimension of the human person, as reflected so beautifully in the basic theme of this conference, I, of course, favor the former. This appeal counters and can prevail over those forces that would disvalue life, encourage death of convenience, or deny resources to those stigmatized by need

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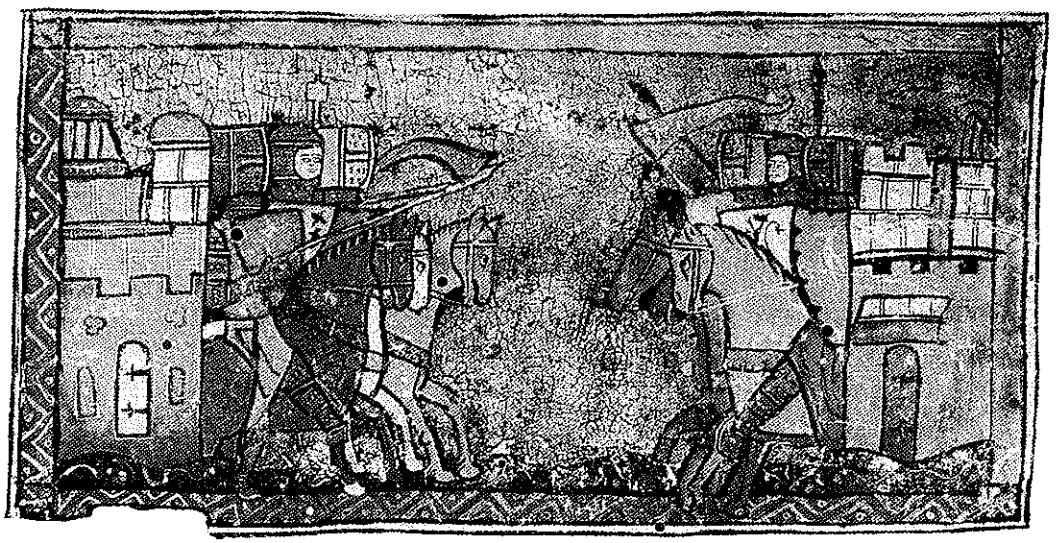

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Autoimmune Diseases

The immunity system protects the organism from aggression on the part of harmful agents which invade it from outside. These defenses are organized in a complex system whose task is to intercept and destroy these agents, whatever their nature may be. It is therefore of great biological and medical interest that the system can experience dysfunctions which are the source of that heterogeneous group of disturbances known as autoimmune diseases, which arise when the immunity system turns against the cellular components of its own body rather than against external agents.

It is thought that the immunity system evolved as an answer to the need of the first multi-cell organisms to recognize other living systems which threatened their survival.

Another requirement of these systems of recognition is the ability to distinguish oneself from what is not oneself. This is a secondary task but of great importance in the immunity system, which is present in all the vertebrates. In the process of evolution the system took on yet another function—the elimination or rejection of all cells which are foreign to the organism itself.

Immunological science, from one point of view, is the science of evolved organisms. During phylogenesis most of the fundamental functions which have permitted the organization of live on Earth as we know it—molecular reproduction, the genetic code, hereditary transmission, enzymatic function, synthesis, and energy degradation —were already present in a perfect state at the time of the appearance of prokaryote and one-cell organisms. During the subsequent evolution of multi-cell beings, the appearance of the nervous system and the adoption of sexual reproduction played a fundamental role. These features guaranteed the development of a population which was always sufficiently different and varied for evolution to be able to make its choices.

Given the fundamental importance that the immunity system has acquired for the most evolved organisms and in particular in our species, each minimal dysfunction in the system provokes incalculable damage to the workings of the different vital functions.

Diseases of an autoimmune character are today recognized as being amongst the most frequent and crippling causes of pathological alterations. In the great majority of cases they are not lethal but with the passing of time they show themselves to be some of the principal causes of long-term handicap.

Amongst the autoimmune diseases which attack the nervous system, multiple sclerosis or sclerose en plaque is one of the most devastating pathologies there is and unfortunately one of the most frequent. It is of great scientific interest because of the questions that it still raises of a therapeutic, etiological, and social character, and because of its role as a crippling and chronic, but not fatal, illness which attacks men and women at the most productive stages of their lives. The disease expresses itself in clinical terms with symptomatological and developmental features which are markedly polymorphous and which range from oligosymptomatic forms to a slow and relatively benign evolution and to other initial serious forms which are quick in their crippling effects.

The symptomatology varies according to the areas which have been most hit and to the speed with which the lesions spread. In the most common forms there is an almost constant localization at different levels of the pyramidal areas and of other neuronal systems with resultant paralysis of the arteries and the cerebral passages, and the appearance of disturbance of balance and motor coordination. Sight and sense deficits, dysarthria, diplopia, optic atrophy, and disturbances of the visceral functions can appear right at the outset or as the disease develops.

The chief histopathological aspect of multiple sclerosis is the presence of multiple areas of demyelination in the central nervous system. These areas are responsible for functional disturbances which can be seen in those who are afflicted by this disease.

Myelin is what covers the nerve fibers present in the central nervous system and the peripheral nervous system of all vertebrates. It is produced and maintained by special glial cells: the Schwann cells in the peripheral nervous system and the oligodendrocytes in the central nervous system. With these cells myelin isolates and binds the axons of the central nervous system. In multiple sclerosis the attacked nervous fibers come to lose this covering, and this causes a very serious alteration as regards their function.

Histopathological study of the areas of demyelination has shown that in relation to these foci there is an increased vascularity and a monocytarial infiltration around the vasa. The areas of infiltration

are made up of T lymphocytes, a lower number of B lymphocytes, and mastocyte and macrophage plasmacells. The areas of inflammation precede the process of degradation of the myelin. This, in turn, is followed by reactive astrocytis, a decrease in the oligodendrocytes, and the disappearance of axons. Products derived from the activation of the complement and immunoglobins are also present in acute lesions. The macrophages in contact with the myelenic sheaths carry antibodies on their membranes. These facts illuminate how important it is to explore the interaction between the various cellular and humoral components of the inflamed tissues.

The hypothesis which is based on these discoveries in vivo and in vitro suggests that the incipient stages of the processes of demyelination are characterized by the presence of cells of an inflammatory nature which respond to stimulants of an unidentified nature, breaking down the hematoencephalic barrier and allowing the complement and other mediators of an immunity character to penetrate the central nervous system. The oligodendrocytes, which are highly sensitive to contact with the complement, and other molecules endowed with the ability to perforate the cellular membranes in the presence of antibodies, experience degenerative processes caused by an increase in intracellular calcium.

With the activation of the complement in the presence of antibodies, the recruited macrophages contribute to tissue damage, releasing cytokines and phagocyting fragments of myelin. Multiple sclerosis can also be seen as a consequence of a vascular alteration (vasculitis) arising as a result of activated T lymphocytes which damage the haematoencephalic barrier.

The forms of treatment used in the light of these discoveries seek to mitigate the inflammatory processes and repress the attacks of the T lymphocytes on the myelin through the use of immunorepressants.

Over the last decade the concept of the functional interdependence between the principal homeostatic systems—immune, nervous, and endocrine—has met with ever greater acceptance. This concept, it may also be observed, has been

further validated by the fact that the pathological alterations of a system affect others through various functional links of reciprocal modulation. In this context, there has emerged the role—which is still undervalued—of a cell which belongs to both the immunity system and the hematopoietic system: the mastocyte. This cell, which is distributed in those cells which are most exposed to influences coming from outside the body, are now recognized as an intersystem interface unit of primary importance. This is because it is regulated by the immune, endocrine, and nervous systems in order act swiftly against endogenous or exogenous noxae of various forms and kinds. The identification of the importance of these mastocytal roles in pathologies with a high inflammatory component element is still insufficiently explored and investigated.

The harmful primer of the inflammatory phenomena which lead to more or less specific lesions to be seen in the various autoimmune diseases is still little understood. In the same way, the mechanisms of modulation, or lack of modulation, of the relapsing or chronic inflammatory processes are not completely known.

The process of degranulation of the mastocyte in conditions of neuromediate or immunomediate hyperstimulation is also, however, a moment of etiopathogenic importance in those pathologies which, although they are not of an autoimmune nature, are characterized by or associated with a state of neuroimmunogenic inflammation in which the components at the source of the activation of the mastocytes are of both a nervous and an immunity character.

In investigating the endogenous mechanisms entrusted with the regulation of such inflammatory processes certain interesting indications have emerged as regards the importance of the endogenous methods of activation and inhibitory control by the mastocytes. With regard to these methods, we have known for decades about regulation at a systematic level by the steroid hormones of the adrenal cortex—an endogenous process exploited massively at a pharmaceutical level with the use of synthetic corticosteroids which are powerful and indiscrimi-

nate anti-inflammatory agents and immunosuppressants.

As regards the origins of the mastocytes, they are tissue cells which are broadly distributed at the connective and mucous levels where they often form close associations with the peripheral nerves and in particular with the terminations which contain substance P.

The mastocytes are a cell population which is highly heterogeneous in terms of localization but also with regard to its physiological and cytological characteristics. Their close association with the nervous tissue, both at a central level and at a peripheral level, suggests a morphofunctional interdependence.

With greater knowledge of these associations between mastocytes and nerves, the concept has gained ground of neurogenic inflammation, an example by now well characterized by interrelation between the nervous system and the immune system. Neurogenic inflammation starts from nervous stimulations of a mechanical character which, through afferent messages and antidromical reflexes, lead to the release by the nerve endings of neuromediators such as substance B. This substance is endowed with the ability to activate the processes of mastocytal degranulation.

In the light of these neurogenic implications one cannot fail to bring to mind another important nervo-immunity influence, that effected by NGF. This factor was originally thought to be involved in processes which were exclusively neutrophic and, in contrary fashion, to have numerous biological effects at the level of organs and non-neuronal tissues. In particular it modulates the immunity response triggered by both the T and the B lymphocytes, induces morphological changes in the blood plaques, stimulates neutrophic functionality, and accelerates the process of scarring.

With specific regard to the mast cells, the NGF is also able to potentiate their degranulation and to act directly on their neurogenic activation, having well-known effects on the development and the functioning of the same neurons containing substance P. Previous studies illuminated another important role: its proliferative impact.

Injections of NGF into newly born rats provoked, indeed, a significant increase in mast cells in various tissues. Furthermore, it has been demonstrated how NGF is able to induce differentiation of the mast cells in the direction of the connective phenotype, where the local microenvironment plays the main role in mastocytal differentiation.

The immediacy of the mastocytal response is an essential characteristic of the physiopathy of these cells, which is based, essentially, upon the availability of intragranular mediators to be secreted following the stimulus—something which, in turn, depends on the type of strategy engaged in by the cell. The mastocyte is, indeed, able to store preformed molecules which are ready to be used rather than having to produce them on each occasion that they are needed. This behavior has been well-known for a long time as regards mediators such as histamine, heparin, and serotonin. It has been demonstrated recently as also being present with mastocytal molecules of a different type. I am referring here to TNF—cytokine characterized by a notable variety of effects and identified in 1987 at the level of the dense cytoplasmatic compartment of rat mastocytes as being responsible for the cytoxicity exercised by this molecule in relation to tumor lines. The TNF is able to induce the expression of a great variety of cellular interaction molecules which are necessary to the amplification of inflammatory phenomena. In the study of inflammatory mechanisms of a high typology, the central role of the mastocytes passed almost unobserved for many years. This was probably because of their upward insertion in the inflammatory sequence and the difficulties found in identifying them histologically once they had reached the stage of degranulation.

In multiple sclerosis the mastocytes which are pathologically active are indicated as being essential elements in the development of the plaques, in the haematoencephalic alteration, in the adhesion of the infiltrating granulocytes of the vasal compartment, and, finally, in the release of aggressive cytokine TNF, which provokes final damage to the myelinic structures and is an important cause of tissue alteration.

The data which have been referred to stress the possibility of an important pathogenic role for these cells both in multiple sclerosis and in other crippling diseases of an autoimmune character. Youth or adult rheumatoid arthritis is one of these diseases which is currently the object of study. This malady affects a relevant number of people, about ten times more than those with multiple sclerosis, and has serious disabling effects.

In rheumatoid arthritis mastocytal activation can be attributed to the substance P, which is released by the local sensor endings. This means that we are faced with another example of neurogenic inflammation where the most important functional unit causing articular damage is once again of the nerves-mastocytes. Extremely interesting data are emerging on this question with regard to the potential pathogenic role of the NGF itself. It has been observed, indeed, that the levels of this neuropeptide in the synovia and the synovial fluid of patients afflicted by rheumatoid arthritis are much higher than normal. This increase seems to be responsible for the large-scale mastocytal proliferation.

The data which have been briefly outlined demonstrate the fundamental role played by the mastocyte in the two autoimmune diseases which have been cited—multiple sclerosis and rheumatoid arthritis.

These pathologies are sustained by a mastocytal hyperstimulation and by connected phenomena of degranulation which cause the release of molecules which have a highly cytotoxic effect.

The hypothesis has emerged that the mastocytal cells subjected to activation of an immunological and/or neurogenic character are the objects of a negative control which reduces their functional activity and is more specific than that exercised at a systematic level by the steroid hormones. This hypothesis has been lent weight by the discovery of endogenous substances which can act as local antagonists of the degranulation of the mastocyte. One is dealing here with a class of chemically identified and recently synthetically reproduced compounds which have the property of inhibiting the degranulation of the mastocytes and thus preventing the toxic consequences of their release of these products.

To sum up, the research carried out over the last years has demonstrated the important role performed by the NGF as an activator of the mastocyte.

At the same time, the fundamental role of the mastocytes in all the processes of immunoneurogenic inflammation has been made clear.

The pathologies to which reference has been made—even though they are of a rather heterogeneous character in relation to each other both in terms of etiology and localization because they can affect different zonal levels—are similar in their expression of the inflammatory processes which cause pathogenic damage.

The phenomenon of mastocytal hyperactivation is taking on ever greater importance in the pathology of autoimmune diseases. The natural or synthetically produced endogenous compounds which operate through a mechanism termed ALIA (Autacoid Local Inflammation Antagonism) can perform an action of great therapeutic potential which is basically completely innovative.

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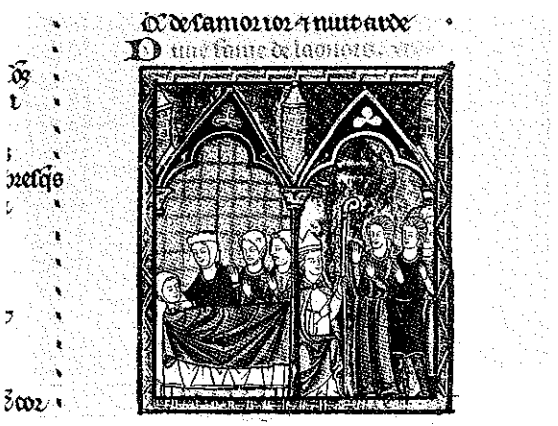


MARY JANE OWEN

The Wisdom of Human Vulnerability (Disability: The Tie Which Binds)

A learned man of God, John Cardinal O'Connor, offered this guidance: Speak from the heart of the experiencing of human vulnerability and wear your disabilities like a mantle about your shoulders.

For two decades I have been a participant observer, contemplating our mutual fragility and struggling to comprehend the foolishness of God's insistence on placing our precious souls into such fragile containers. Our efforts to avoid recognition of our frailty speaks loudly of our sense His choice was an oversight and certainly imprudent. The never-ending search for the Fountain of Eternal Youth tells the story of our dismay. We find it difficult to accept the reality that we face eventual physiological disintegration.

This paper suggests that some of the conceptual lenses through which we have traditionally viewed our own and other's vulnerabilities distort and frighten us. The old prescriptions blur our vision of our need to foster interdependency. There is little need for the fear which stalked our ancestor's nightmares. Current medical and rehabilitation technology and techniques can assist our brothers and sisters; sons and daghters; husbands and wives; mothers and fathers to remain interactive and involved with those whom they love and who love them as various functions diminish or are lost. I do not propose an end to our efforts to reduce suffering, only that we approach those challenges with deepened awareness that vulnerability may be an essential component in God's plan for us.

The judgement " I'd rather be dead than disabled " is a painful reminder of the low value placed upon our lives. And this troublesome refrain collides with our views about the sanctity of life. For it fuels those outmoded fears about unwanted dependency which are associated with " infirmities " and moves people to choose death over inconvenient life. Whether a given eugenics campaign endorses euthanasia, infanticide, or amniocentesis and abortion, potential colleagues are easy prey to each retelling of the ancient and no longer appropriate terror. The assaults upon life move forward because so few of us are knowledgeable or comfortable enough to speak out positively about the power of the powerless and the potential of those who are disabled.

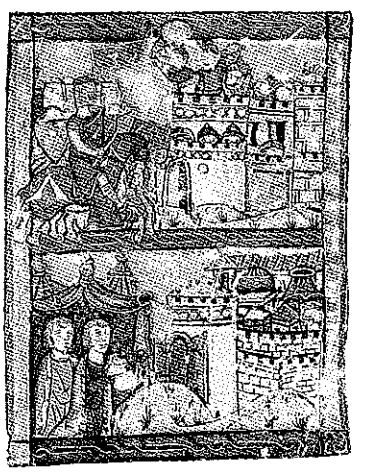
And the pious reinforce this negativity as they mutter, " There but for the grace of God go I, " failing to recognize the verdict they have leveled against those who live with disabilities and who may still be well within the circle of God's grace and love.

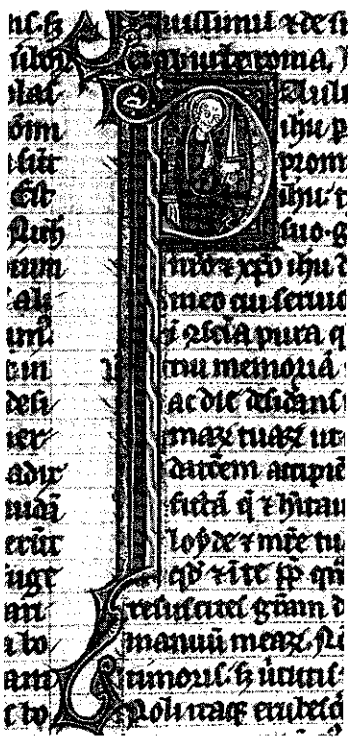
Against this sketchy background, let us quickly examine a few conceptual lenses which have been reground by advocates in the United States:

1. A shifting paradigm replaces the medical model, which sees those with impairments as " patients " whose needs must be met in " special " ways with a political, socioeconomic alternative which conceptualizes the environment as the handicapping factor.

2. The definition asserts: " Disabilities " are the normal and anticipated outcome of the risks, strains, and stresses of the living process itself. Therefore, the condition ceases to be merely an individual tragedy and becomes an expectation within any community.

3. The symbol of the Cross is essential to our Faith, but we are the Easter people who look beyond Calvary to the sunrise of that glorious dawn when the heavy stone blocking our view of His power and grace was rolled away. The old association of disabilities with the suffering Christ can be expanded to include the miracles of rehabilita-





tion as small reminders of His Resurrection. Thus we confirm we are a part of His Body and our souls strive to prove His power.

4. Each time words of pity target those with disabilities the message of inclusion is blunted. Pity limits, shames, and never elevates the one toward whom it is directed. It is an unwanted projection of society's fear and discomfort. Respectful compassion and mutual recognition of our shared fragility must replace it if we are to become united as people of God.

5. The fifth lens is pivotal if we are to justify the challenge of the current presentation, for a new prescription calls for a lens which can focus on the power of human vulnerability. Until we recognize this trait as valuable to the health of any organization, we will lack motivation to alter our current patterns of exclusion and separateness.

Our vulnerability, which has been encoded into our gene pool, is the catalyst which brings us into community and church with renewed recognition that we need each other and our Lord. When God tied the gift of life to the trait of vulnerability, He may have given us the only incentive which could counter our tendency toward disregard of the rights and value of others. When we see ourselves in our peers, we are joined in a bond which comes from the heart.

When we are unaware of or deny our interconnectedness, we move about functioning as if our souls had been placed in high impact plastic bodies. We tend to become alienated and solitary, mistaking independence as the source of power. We take a " kleenex " approach toward life, justifying its disposal when it becomes less than perfect.

It is through synergy and mutual aid that communities are built and maintained. Without the evidence of our own weakness and fragility, many of us would ignore the message of unity and interaction. When Christ called upon us to seek the safety of the fold, the message was of our need, not our ability to thrive in isolation.

On a personal level, I saw no value in vulnerability when it began to creep upon me in 1972. I was focused on a professorial title. Everything of importance seemed tied to my visual acuity and photographic memory. I was a brilliant scholar and now my opportunities were slipping away as my vision faded.

An academic colleague tried to comfort me with these words, " When Caesar Chavez goes out to organize the migrant farm workers, he always asks for a match although he doesn't smoke. " Such a simple request pricked the surface of that bubble of tension which separates us from each other. A modest need was the " excuse " for starting a serious dialogue.

I heard no comfort in my friend's words. He was telling me that as a blind woman I'd have to go through life asking for help. That image had nothing to do with my view of power and autonomy. Not surprisingly, I lapsed into self-pity, " I'd rather be dead than have to go around asking for help all the time! " But God had many more lessons for me than I could have imagined.

And so one day I had to travel alone to another city. I moved through the doorway into the huge bus terminal barely touching the floor with my white cane. I hoped no one would notice I was blind.

The trip to the counter was uneventful but then I had to utter the dread words. The results was worse than I'd imagined. The man pulled down the microphone and out boomed my embarrassment: " Will someone please help this blind woman catch the bus to Sacramento? "

The cavernous space had seemed oddly silent. One knew there were people waiting on the hard benches, but no one spoke. Then suddenly all that changed. " Here, let me help you to a seat, " someone said. And as we passed the previously silent bodies, there was a buzz of chatter. " I'm going to Placerville to see my granchildren, " was greeted with the news of a young man's trip to Quincy to check out the college there. The room which seconds before had been like a

tomb of anonymity was transformed into a gathering place for friendly travellers, all sharing a few words to ease the boredom of their wait on a journey to somewhere else.

That was not the final lesson. I sas a slow learner but with each venture realization grew. When I gave myself permission to ask for help, those around me were given the " excuse " they needed to feel needed. Amazing, but my vulnerabilities were the catalyst which gave others permission to unite: to behave as community

" How come you know so many people? " " Because I have to move out each day, trusting that minor miracles of happenstance will occur again today. When depending upon chance encounters allows for one's freedom to come and go, there are few strangers in one's path. "

When people move out into their world in such a manner, they are catalysts and confirmations of mutual need. Can there be any doubt we need that fragility which can unite us? For, as a society, we are sickened by alienation and solitude. But until we throw away some of the dysfunctional myths and fears, we will not profit from the richness of God's gift.

Too many individuals with disabilities have awaited their turn to worship and to serve their Lord. Too often the Good News has been proclaimed behind barriers we could not overcome and our potential contributions have gone unnoticed. Upon signing the Americans with Disabilities Act, our President told the thousands assembled on the White House lawn that this law was a sledgehammer with which to smash the ancient walls which had blocked 43 million people from fulfilling their dreams and offering their gifts to the nation. That wall of prejudice and fear extends around the globe, separating and segregating.

A united resolve to smash the old conceptual lenses which blurred our vision of the power of human vulnerability can destroy the old prejudices. We must constantly remind ourselves that God's gift of life is placed in fragile earthen vessels to a powerful purpose. We have only to recognize and celebrate that reality, and it will free us from past fears.

For it is our common recognition of interdependency which weaves the threads of our societies together. Each time one of us feels needed and essential to another, the threads of that interaction are reinforced, and the fabric which holds us together as Church and as society is powerfully strengthened.

There is wisdom in vulnerability, and it will bind us together powerfully, if we will only look at reality with fresh vision.

May God bless our crusade.

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Equalization of Opportunities for Disabled Persons: From Awareness to Action

Ten years ago, the General Assembly of the United Nations proclaimed its Decade of Disabled Persons, which is now coming to a close. Indeed, one could not think of a better major event of its closing months than this Conference. Bringing together the world's prominent experts, representing as they do different persuasions, backgrounds, and cultures, has placed our Conference among the most important awareness-raising and professional events of the Decade. I wish to pay a well-deserved tribute to the Pontifical Council for Pastoral Assistance to Health Care Workers, under the leadership of His Eminence Florenzo Cardinal Angelini, for the enormous effort of convening this historic Conference, which it is a privilege to attend.

We are here today, united in a consensus around the belief, so eloquently expressed by His Holiness John Paul II, that *" the disabled person is one of us and participates fully in the same humanity that we possess. It would be radically unworthy of man, and a denial of our common humanity, to admit to the life of the community, and thus admit to work, only those who are fully functional. To do so would be to practice a serious form of discrimination. "* Could one think of a more cementing link for a conference like ours than those words of wisdom, which we all subscribe to?

Our consensus also rests upon the belief that disability need not be a handicap; that disability is not so much about personal deficiencies, which we all possess to some degree, but about the frequent failure of environments to accommodate those defficiencies. Many persons' opportunities to live a full life rest on the redesign of environments. Handicap is thus a function of the relationship between persons with disabilities and their environment. It occurs when they encounter cultural, physical, or social barriers which prevent their access to the various systems of society that are available to other citizens. Handicap, therefore, is the loss or limitation of opportunities to take part in the life of the community on an equal level with others. It is a function of the relationship between persons with disabilities and their environment.

A Unique Evolution

The past decade has witnessed a unique evolution of approach to disability issues. We are at the moment in a very crucial phase of the process. For too long, ignorance, neglect, intolerance, superstition and fear have shaped the fate of many of our brethren with disabilities. Historically, the process has progressed from prejudice and charity, through a mainly health-oriented approach, to equalization of opportunities and full integration into society, towards the well-being of all. Its best synthesis and its conceptual revolution

has been reflected in the World Program of Action developed by the UN ten years ago; its basic philosophy is one of conceptualizing the role of the human being, disabled or not, as a purpose-oriented agent. The well-being of such an agent cannot be ensured by following approaches which meet basic needs alone. The World Program of Action, as an expression of a new social policy framework, challenges outdated passive and incapacitating approaches.

Of major importance has been the role of people with disabilities themselves, telling the world: *" What is this life if, full of care, we have no time to stand and stare. "* They and their organizations have become a driving force in developing policies on disability.

Equalization of Opportunities

The principle of equalization of opportunities for disabled persons has emerged as the philosophical and practical pivot around which disability policy is evolving. It is the process through which the various elements of society, the physical environment, services, activities, and information are made accessible to all, including disabled persons. This means the full integration of people into the mainstream of society; it means a focus on personal potential rather than a fixation on limitations; and it calls for the building of bridges to participation and the destruction of barriers hindering that process.

An inherent part of equalization of opportunity are equal rights:

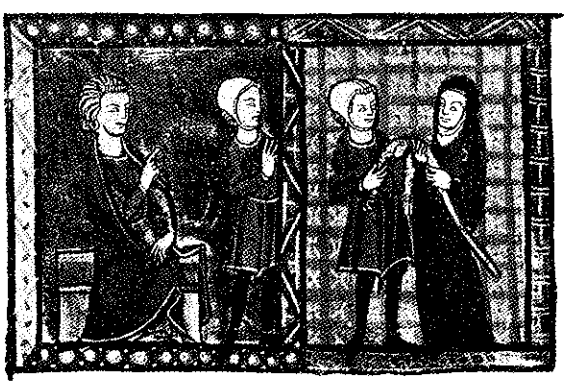
Firstly, persons with disabilities have the same basic rights as all other persons. If we neglect the basic human rights of any person, we are all degraded by the experience—we all become accomplices to the violation. The principle of equal rights for disabled and non-disabled persons implies that the needs of each and every individual are of equal importance, that these needs must be made the basis for the planning of societies, and that all resources must be employed in such a way as to ensure, for every individual, an equal opportunity to participate.

Secondly, disabled persons have an inherent sensitivity and first-hand knowledge of disability matters. Accordingly, they must have the right to make decisions about their own destiny and not be denied the opportunity to participate in decision - making.

Thirdly, persons with disabilities have the full right to live and participate in society, to remain within their own communities, and to receive all the protection they need to function within them. Disabled or not, our bodies are equal as temples of the human, creative spirit.

Fourthly, society has an obligation to not only remove the barriers to full and equal participation, but is also bound to provide the means to make participation, integration, and equalization a reality.

Finally, as persons with disabilities have equal rights, they should also have equal obligations and should be entitled to assistance in assuming their full responsibilities as members of society.



There are several preconditions for equal participation:

1) *Awareness-Raising*

Governments and all other social institutions should take action to raise awareness in society about persons with disabilities, their rights, their needs, their potential, and their contribution. Up-to-date information on available programs and services to persons with disabilities, their families, professionals in this field, and the general public should be readily accessible and disseminated. The language used by the mass media should portray persons with disabilities with the same degree of objectivity as that of the general public. Similar elements ought to be included in all relevant public education programs. Likewise, much is still to be done in terms of raising the level of awareness of persons with disabilities concerning their own rights and potential for self-reliance and empowerment.

2) *Medical Care*

States should ensure that persons with disabilities are provided with the same level of medical care within the same system as other members of society. They should also ensure that persons with disabilities are provided with the regular treatment and medicines they

need to preserve or improve their level of functioning.

3) *Rehabilitation*

National rehabilitation programs should be available to all groups of persons with disabilities. it is particularly important that such persons and their families be able to participate in the design and organization of rehabilitation services concerning themselves. At the same time, persons with disabilities should be encouraged to involve themselves in rehabilitation, for instance, as trained teachers, instructors, or counsellors.

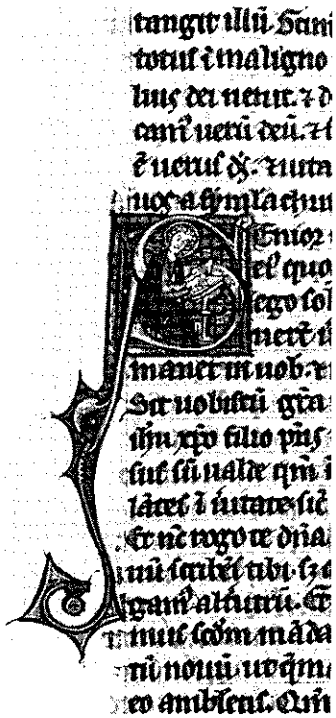
4) *Support Service*

All persons with disabilities are entitled to technical support, personal assistance and interpretation services, according to their needs. Here again, personal assistance programs should be so designed that persons with disabilities using the programs have a decisive influence upon the ways in which such programs are delivered.

Targets for Equalization of Opportunities

Basic to the concept of equalization of opportunities is accessibility, in terms of both access to the physical environment and access to information and communication Mesasures to remove the obstacles to participation in the physical environment, to develop standards and norms for accessibility to various areas in society, including buildings, means of transportation, streets, and other outdoor environments are of crucial importance in equalizing opportunities. The same is true of the need for strategies to make information services and documentation accessible for different groups of people with disabilities.

Equal *educational opportunities* for children, youth, and adults with disabilities, in integrated settings, represent a second most important aspect of the subject at hand. Integrated education and community-based programs should be seen as complementary approaches in providing cost-effective education and training for persons with disabilities. Special schools, if required, should have the same goals as ordinary schools, that is, to make the best of a child's potential.



Employment as an important instrument of enjoyment of human rights should be seen as the next important element of the process. Persons with disabilities, both in rural and urban areas, must have equal opportunities for productive and gainful employment in the labor market. Laws and regulations on employment must not discriminate against them, nor should they raise obstacles to their employment. An effective course to follow is a well-conceived integration into the open labor market.

Target areas for equalization of opportunities also comprise income maintenance and social security; family life and personal integrity; culture; recreation and sports; as well as religion. This implies that Governments are responsible for ensuring the provision of social security and income maintenance for persons with disabilities. They should promote the full participation of people with disabilities in family life, showing respect for disabled people's right to personal integrity, marriage and parenthood. Those latter aspects are of particular importance also in the context of the forthcoming International Year of the Family, 1994.

States, too, are responsible for ensuring that persons with disabilities can participate on an equal basis in cultural activities, which utilize their creative, artistic and intellectual potential, not only for their own benefit, but for the enrichment of their community as well. Governments should also initiate measures to make recreation and sports places accessible to people with disabilities.

Last but not least, equal opportunity and participation imply unhampered access by persons with disabilities to the religious life of their communities. Information on disability matters should be available to religious institutions and organizations; it should be included, too, in the training of priests and church leaders, and in religious education programs.

Modalities for Implementation

Any comprehensive program seeking the equalization of opportunities has to be based on a set of well functioning and effective measures, for which the ultimate responsibility rests with governments and other institutions of public life. These measures include:

— the collection and dissemination of information about the living conditions of persons with disabilities and promotion of research on all matters which affect the lives of such persons;

— the inclusion of disability considerations in all relevant policy-making and national planning;

— the establishing of a legal basis for measures to achieve the objectives of full participation and equality of persons with disabilities;

— the financing of national programs and measures for the equalization of opportunities;

— the establishment and strengthening of national coordinating mechanisms to serve as focal points on disability matters;

— the recognition of the right of organizations of persons with disabilities to represent disabled persons at national, regional, and local levels, and recognition of their advisory role in decision-making on disability matters;

— the continuous monitoring and evaluation of the implementation of national programs and services concerning equalization of opportunities for persons with disabilities;

— ensuring adequate training of personnel, at all levels, involved in the planning and provision of programs and services concerning persons with disabilities; and, finally;

— enhancing technical and economic cooperation at both national and international levels.

The United Nations at the Forefront

Although the international community is still far away from its goal of equal opportunity, the last ten years have seen unprecedented progress in raising the awareness of the need for equal rights and full participation of persons with disabilities. The United Nations, within its modest budgetary resources, has been at the forefront of the campaign. Starting with the adoption of the World Program of Action and following several other projects, the crowning point has been the elaboration, this year, of draft Standard Rules on the Equalization of Opportunities for Disabled Persons, a document of unprecedented dimensions, to be presented to the General Assembly, next year. The draft Standard Rules have been developed on the basis of experience gained internationally over the past decade. Once adopted, they will form a strong moral and political commitment by States to take action towards the equalization of opportunities of persons with disabilities. They will also set minimum standards for the treatment of an important social group in society and provide measures against which governments will be able to gauge their progress.

Together with the World Program of Action concerning Disabled Persons and the long-term strategy for the Program's implementation, the Standard Rules will guide the United Nations disability effort towards the second millennium.

Our long-term objective is a *Society for All by the Year 2010*. Such a vision of a Greater Society implies a basic change in thinking and in accommodating differences in our societies today. A key to sustainable development is to capitalize on human potential precisely by creating equal opportunities for full participation.

End of an Era—New Beginning: From Awareness to Action

The end of the United Nations Decade of Disabled Persons marks a new era in the disability field. The past ten years laid a solid foundation, a launching pad, for concrete practical and effective measures to realize the full and equal participation of disabled persons. The Decade has also laid the foundations for the development of a comprehensive integrated policy approach

at both the international and national levels, through an increased awareness and sharing of information on disability issues

Consequently, a new approach has been forged—one which focusses on ability rather than disability and on integration rather than segregation, on fully developing potential rather than maintaining hurdles to development and participation.

What we need now is action at all levels, in order to put into practice, in deeds, not just in words, the numerous standards and principles elaborated by both the international community and many national governments.

Guided by sufficient political will, all governments should commit themselves to designing appropriate, integrated policies and to setting up their own realistic agendas for action. International funding agencies should more seriously become involved in assisting effective programs and projects on disability. The United Nations itself ought to be equipped with mandates strengthening its role as a facilitator, coordinator, and catalyst of action. This is one of the basic requirements of the present phase, if the family of nations is to reach its ambitious objectives of the year 2000 and beyond. As in many other areas of human endeavor, in the field of disability the United Nations cannot be in a position to solve problems singlehandedly, exclusively on its own. Its role is to show the way. Do we know how to do this? Yes, we do. Do we have good programs of action and clear objectives? Yes, we now have; because they have been enriched by and reflect the collective wisdom of the international community. Let us not lose time in putting them into concrete action—together

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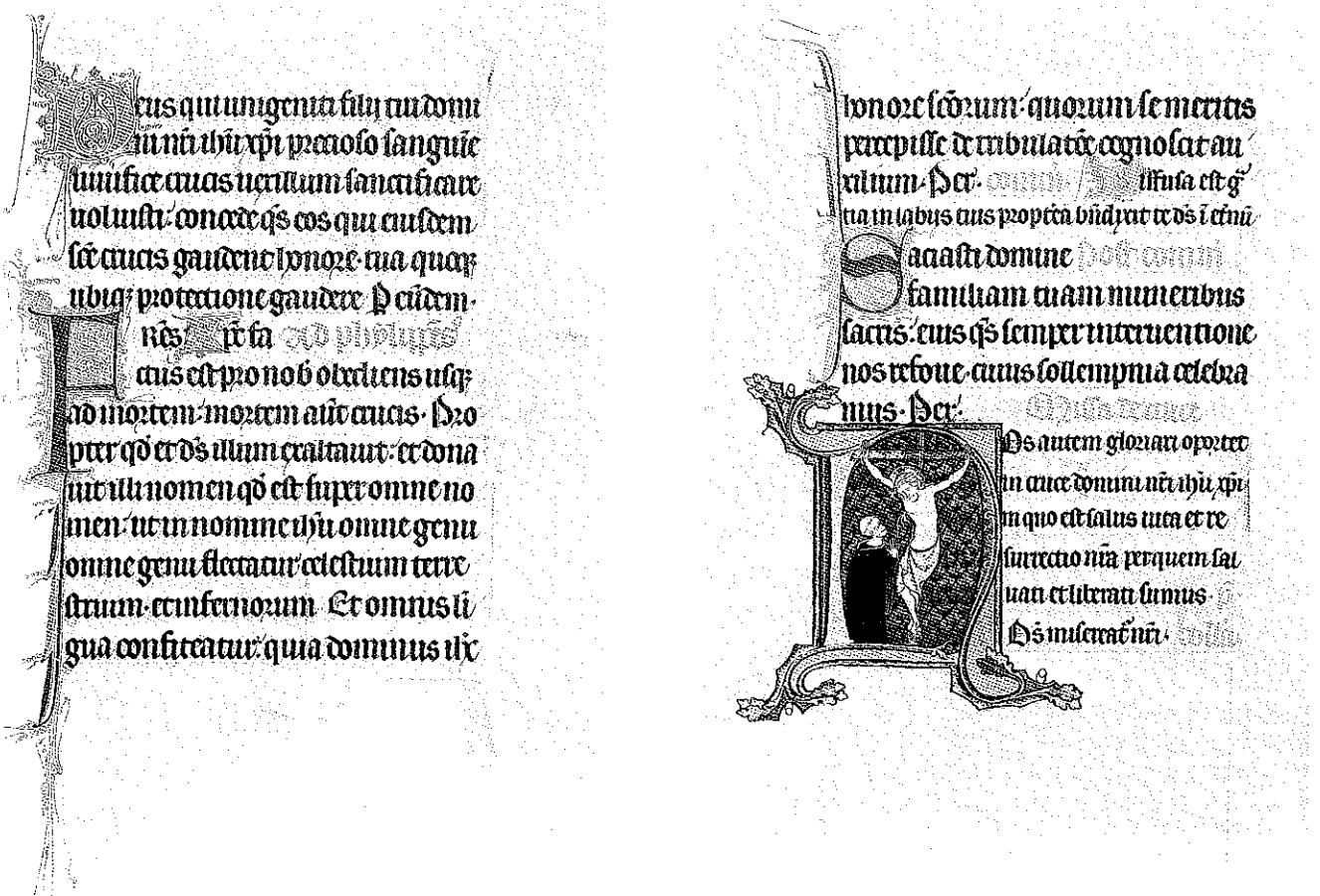


MARY KEANE

Community Life

I. INTRODUCTION

Over the past two decades the concept of community-based services and in particular the concept of community-based housing versus the traditional residential model of living for people with learning disabilities has gained international momentum. Indeed, some governments control their funding allocations on the criteria that services receiving funding must demonstrate commitment to the community model.

The principle of normalization which underlies or leads the community-based movement was first introduced by Nirje (1969) (1). Of course, this is not to say that community-based services did not exist prior to Nirje's introduction of the concept of normalization. Normalization is based on the proposition " that the quality of life increases as access to culturally typical activities and settings increases " (2).

Nirje (1969) defines normalization as: making available to the mentally retarded patterns and conditions of everyday life which are as close as possible (3) to the normal patterns of the mainstream of society.

This definition places *responsibility on service providers* to develop community-based services which provide particular social opportunities for people with learning disabilities.

The normalization principle grew out of, or supports the belief that, in general, society tends to reject some of its members because' of their differences. It is suggested that the development of segregated and in some instances poorly funded facilities/services is a result of this societal rejection.

An example of this was the establishment of the first institution in the United States (1848) and the subsequent proliferation of institutions thereafter. This development was strongly influenced by the Eugenics Movement.

In 1972, Wolfensberger defined normalization as:

—the utilization of means which are as culturally normative as possible in order to establish and/or maintain personal characteristics which are as culturally normal as possible (4).

In this definition the focus is on " the individual, not the service provider. "

In 1983, Wolfensberger introduced the concept of social role valorization (6) through which he emphasised the promotion of *valued social roles* for people who are at risk of being devalued. Wolfensberger maintains that the valued social roles develop from 1) enhancement of people's self-image, and 2) enhancement of their perceived competencies. A number of research studies have identified that while people may achieve both premises, this does not necessarily lead to acceptance of their role in society on a socially valued basis.

There are many issues around the principles of normalization and social role valorization. Some such issues might be the following.

— In our efforts to uphold the principles of normalization, do we tend to deny the reality that people do indeed have differences, be they overtly or covertly manifested, and if so, are we in danger of supporting the concept that to be different is not an acceptable social value?

— Do we believe and promote the idea that people with learning disabilities should experience the negative, debilitating, and often dehumanizing aspects of societal values/norms as well as those which are positive?

— Do we fully comprehend the implications for people with learning disabilities regarding self-advocacy, decision-making, choices,

risk-taking, dignity, respect, quality of life, and personal fulfilment?

— Do we tend to vocalize/ espouse the practice of the principles of normalization/social role valorization but not actually be committed to bringing them to life?

— What implications does active commitment to the principles of normalization have for families, staff, and the community?

These are but a few of the issues to which we must be alert when developing, implementing, and evaluating the community-based model of living.

The focus of this paper is to share with you the development and current status of the community-based residential accommodation provided and administered by the Hospitaller Order of St. John of God in Ireland and the resulting quality of life experienced by the residents. To do this, I need to give you some background on the national developments regarding community-based residential services and a short overview of the totality of the Order's services in the Irish Province.

II. NATIONAL LEVEL

Since the 1970s Ireland, like other countries, has been promoting the development of community-based residential services as an alternative to the traditional segregated residential model.

However, it was not until the latter years of the 70s and the early to mid 80s that there was any notable increase in the provision of such services. A study by the Health Research Board shows that between 1971 and 1985 approximately 100 community-based residences were established throughout Ireland. Approximately 500 people were accommodated (7).

I should note here that these figures relate to domestic style dwellings located in the normal community residential areas which accommodate no more than ten people. They do not take into consideration other community-based residential models existing at the time of the study.

The Health Research Board study also identified that a higher number of community-based residences were located in urban areas. The development of these community-based residences demonstrated that people with learning disabilities could indeed live successfully in the community and that community-based living was a positive and enriching experience for them. This led to a strengthening of the national interest in maintaining the concept of community living. This interest was given substance through the development and publishing of various national documents and policies which promoted the community-based residential movement.

One policy document worthy of mention in this context is the document developed by the National Association for the Mentally Handicapped in Ireland (a Parents and Friends organization). The impetus for this Policy Document came in 1988 from one of the St. John of God Order's Parents and Friends Associations. The President of the National Association for the Mentally Handicapped in Ireland at that time was a St. John of God Brother.

Hospitaller Order of St. John of God—Irish Province: Service Provision

The St. John of God Order began providing services in Ireland for people with learning disabilities in 1930.

Currently, the Order in Ireland provides services which address the needs and abilities of people who have intellectual, psychological, ageing, or health-related problems. The age range of people served is from shortly after birth until death.

The continuum of service components encompasses:

Traditional Residential Services
Community-based
Residential Services
Day Services
Special Schools Respite Services
Crisis Services

Currently, a staff complement of approximately 1500 people, which includes Brothers (45), enable the Order to develop and deliver these services.

The Order's services are established in 6 of the 26 counties of the Republic of Ireland. The hub of the service is located in Dublin, Kildare, and Wicklow counties, all within a radius of 15 miles (24 kilometers) from the Provincial Curia, Dublin. The remaining three locations (Counties Louth, Monaghan, and Kerry) are 50 (80 kms), 75 miles (120 kms), and 180 miles (288 kms) from Dublin, respectively.

III. DEVELOPMENT OF THE ORDER'S COMMUNITY-BASED RESIDENCES

I will now focus on the development of the Order's community-based residential service, the profile of the residents, and a description of the service aims and activities.

The Order currently administers a total of 45 community-based residences in Ireland. These are located in three different geographic sectors. The sectors have been determined by the unique needs of the population in those sectors and notably influenced by the existing presence of an Order service. For ease of reference I will speak of these as Sectors 1, 2, and 3. Sector 3 will be my main focus in this presentation.

In Sector 1 we have three group homes which provide community-based living accommodation to seventeen young adults, eleven of whom are male and six of whom are female. These are currently 5-day residences. Two of the residences have both male and female residents.

Sector 2 currently provides twelve group homes and accommodates fifty-two residents. The age range is from 14 to 67. There are 46 males and 7 females. The degree of intellectual disability ranges from mild to severe, but most people function in the moderate range of learning disabilities.

Three of the twelve homes have a male and female mix of residents.

Eleven of the twelve homes are staffed at night. One person lives totally independently with distant occasional supervisory support accessible to him.

I will now address in depth the service provision located in Sector 3, the profile of residents, and the results of a survey completed by the residents regarding their views of their experiences of community living.

Model of Service

The aim of this activity is to provide a community-based residential service which makes available to individuals norms and patterns of life similar to those of all citizens.

The people live in ordinary houses, in ordinary streets. The service provides facilities to people who have a wide range of learning disabilities. The design of the houses, staffing levels, and program content are in accordance with the ability levels of the residents and their future goals.

Each staff member in the service is committed to facilitating each individual reaching his/her full potential and living a good quality of life. The Order's policy on labelling and the preferred use of language which enhances the dignity of the person is actively promoted by staff (8). The holistic emphasis in the community-based services is promoted through the Order's Pastoral Care program. The service activities are designed to promote actualization of the following five key principles of normalization:

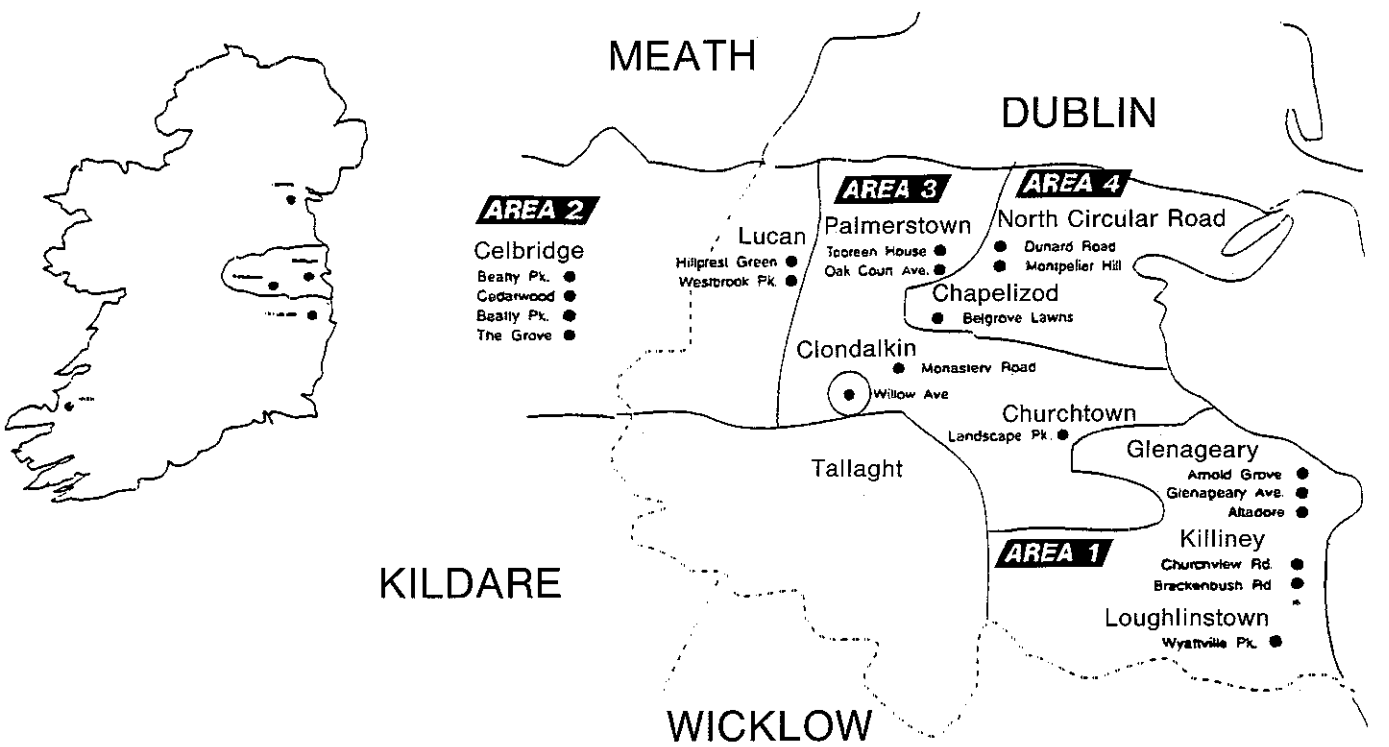
Participation: The person is involved in the planning and evaluation of life and individual programs in association with family, staff, and other agencies concerned.

Choice: Making available real choices for the person, facilitating informed decision-making, and taking calculated risks.

Integration/Inclusion: Encouraging the person to use the facilities in the locality and thus developing the local communities' understanding and awareness of his/her value as a person.

Relationships: Supporting the growth of individuals in their relationship with family, friends, peers, the staff, and those others with whom they have daily contact.

Personal Development: Supporting each person in learning and making use of new skills, thus promoting his/her emotional and psychological well-being and thereby increasing positive self-image and sense of being personally valued.



Activities

These activities aim to increase the person's sense of achievement, companionship, and well-being, and are an integral part of ongoing personal development plan.

1. Advocacy

The residents are supported and encouraged to develop the skills necessary to exercise their rights, express their opinions, and to speak out on their own behalf. Because of our commitment to this philosophy, individuals are encouraged to benefit from a wide variety of experiences, which enhance their assertiveness and self-confidence. The following are two examples of initiatives collaboratively undertaken by residents and staff:

1.1. *Social Partnership Scheme*

In 1989, a nine-month pilot project was initiated with the agreement of two residents who wanted to live more independently but were uncertain about their ability to do so.

The project involved the sharing of a house by these two people and two people who did not have learning disabilities. The aim of the project was to provide the people with learning disabilities an opportunity to experience a lifestyle which

a) had minimal staff supervision;

b) modelled normal peer interaction; and

c) promoted their independence.

While there were initial difficulties (e.g. management of epilepsy), both benefited enormously from the experience and now live independently.

1.2. *People First* (U.K. initiative)

In 1990, a residents group formed their own " People First " committee. The aim of the committee was to provide support to

Table 1 - Statistical summary

	1985	1986	1987	1988	1989	1990	1991
Clients	40	62	66	70	74	89	94
Staff complement	17	23	25	25	30	46	60
Houses	7	11	13	13	14	19	10
Flats	9	9	11	10	10	10	10

Table 2 - Age of clients

Age	0-10	11-20	21-30	31-40	41-50	51-60	61-70
30				/			
				/	male	female	
25				/	2	1	under 10 years
				/	10	6	11 - 20 years
20			/	/	20	8	21 - 30 years
			/	/	32	4	31 - 30 years
15			/	/	6	1	41 - 50 years
			/	/	3	0	51 - 60 years
10		/	/	/	1	0	
		/	/ -	/			
5		/ -	/ -	/ -	/		
	/	/ -	/ -	/ -	/ -	/	
	/ -	/ -	/ -	/ -	/ -	/	/

/ male - female

Table 3 - Male/female client ratio

	1989	1990	1991
Female	7	17	20
Male	67	72	74
Total	74	89	94

Table 4 - Numbers of clients receiving 5 and 7 day service

	1989	1990	1991
5 day	23	26	13
7 day	41	53	71
rented accommodation	10	10	10
Total	74	89	94

members on matters related to their everyday living: health issues, education, employment, social and recreational activities.

Following contact with " People First " in the UK, a decision was taken to send representatives to the UK conference. Fundraising events were organised with the assistance of some of the residents. Two members accompanied by one staff member participated in the week-long conference. Many issues of concern were debated during that week, including employment, education, labelling, and breaking down barriers.

Since their return, the men have kept contact with their English counterparts and have visited the " People First " group in Northern Ireland. One of the two men on return decided go back to his own county. He has since been successful in setting up his own home in his native town. Recently he celebrated his birthday in his own home. He personally issued invitations to his friends and neighbors. His neighbors all helped him to host his party. He is known by all in the town and at his discretion engages in meaningful work with the local businesses. He is very happy and personally fulfilled. This was a dream he always had, but prior to his experience with the U.K. Conference—People First—he had doubted his ability and did not have the courage to share his dream with others.

2. Friendship Scheme: Developing a Network of Friends

This scheme was developed to enable individuals who were unable to actively initiate contact with peers outside of the staff circle.

The aim of the Friendship Scheme is to identify and establish links with people interested in sharing time and leisure activities with our service-users on a voluntary basis.

Contacts have been made with people through the various advertising media (posters, Cablelink TV, and by direct contact with schools, clubs and colleges).

Table 5 - Ownership of cuallacht eoin houses

	1989	1990	1991
Owned by Order	9	12	17
Rented	2	4	—
Eastern Health Board property	1	1	1
Dublin Corporation property	2	2	2
Totals	14	19	20

N B : numbers do not include the administrative offices of the Service

Approximately twenty people are now involved in the Friendship Scheme.

Every effort is made by staff to support both parties in these relationships to ensure that the experience is mutually satisfying.

3. Social and Recreational Activities

Individuals are actively supported and encouraged to become involved in local social and recreational activities.

Many have become quite competent in shopping, using public transport, local library, church, leisure center, snooker club, bowling alley, or swimming pool. Weekends away, holidays in Ireland and abroad, are enjoyed by quite a number, some of whom may go with a friend; others are accompanied by staff members and volunteers. Some keep close contact with the friends they have made through the years and from whom they have now separated due to change of workplace, etc. This contact is maintained by the many enjoyable nights shared in " The Club, " discos, and parties which are organised within the Order's services. This latter location and socialization with peers who have similar disabilities is not promoted within the principle of normalization. I will refer to this dilemma regarding social integration in a later section of this paper.

The service promotes the maintenance of family links and considers this to be essential.

4. Individual Goal Setting

Development and progress assessment of each individual's short- and long-term life goals are undertaken by use of the S.T.E.P. (Skills Training Education and Program Planning) Assessment and Life Planning Program. Each individual's life goals are collaboratively determined. The service activities support the achievement of these goals. The degree to which the quality of life experienced by each person is enriched is a measurement (benchmark) of the quality of our services.

IV. RESIDENTS' PERCEPTION OF THEIR LIFE OPPORTUNITIES

I will now outline for you the process whereby thirteen residents participated in evaluating their experiences in relation to their quality of life resulting from residing in the community and discuss the findings. Finally, implications for the Order's community service planning process and staff development will be discussed.

In 1992, a survey was completed with thirteen community-based residents to find out how they as individuals perceived their lives and experiences.

Interviewees

All interviewees were male and aged between 30-52 years. Ten men were functioning within the mild range of intellectual disability, and three were within the moderate

range of intellectual disability. Four men had Down's Syndrome.

Employment

3 men were in sheltered employment.

1 was in supported employment

1 was in semi-supported employment.

4 were in open employment.

2 were unemployed.

2 were retired (one of whom took early retirement).

Accommodation

8 men lived in shared accommodation (i.e. 3 or 4 shared a house).

3 lived alone.

1 rented his own accommodation.

1 owned his own house.

Interview

Interview Schedule

The interview schedule was designed to examine the following life areas:

* Awareness and use of community supports and facilities.

* Skills necessary for independent living and control of environment (menu planning; money management; mobility; hygiene and domestic tasks; health; literacy; telephone usage).

* Social contacts and relationships.

* Employment.

Additional Questions:

1. What do you think of living alone?

a) Do you feel you get enough support from staff?

b) If not, how do you feel your needs could be met?

2. Which, from all that we have been talking about, gives you the greatest satisfaction or makes you happy?

3. Anything else?

4. What sort of learning do you think is essential or what can schools, training centers, and group homes do to make living alone easier?

5. Are there any particular areas that you feel you would like further education on, e.g. sexuality...

6. If you had three wishes, what would they be?

Profile of Interviewees

Person	a	b	c	d	e	f	g	h	i	j	k	l	m
Sex	m	m	m	m	m	m	m	m	m	m	m	m	m
Age	35	46	42	40	35	45	43	42	37	38	52	35	42
Degree of i.d.	mod ds	mod ds	mild	mild	mod ds	mild	mild	mild	mild	mild ds	mild	mild	mild
Verbal skills					v.p								
Sheltered employment		*			*					*			
Supported employment												*	
Day activity													
Open employment					*	*	*	semi		*			
Unemployed				*									*
Retired			*										*
Shared accommodation	* 4	* 4			* 4	* 3	* 3	* 3		*		* 1	
Living alone			*	*					*		digs		
Rent own accommodation			*										
Owns own accommodation													* 3-bed house

7. What sort of future plans or goals do you have for yourself?

Method of Interview

The interviewer was a staff person who knew the interviewees well and therefore could rephrase questions and reflect back interviewees' comments for clarification purposes.

Interviews were conducted on an individual basis at a mutually convenient time.

Responses were tape-recorded with the interviewees' permission and then transcribed into written format by the interviewer. The written material was then organized by the process of content analysis.

Findings

1. While all interviewees are residing in the community, the majority have not experienced full social integration. This is most noticeable for those who live alone.

2. Loneliness is a critical factor for those who live alone. Their personal contacts tend to be around staff. Some people, while stating that they liked meeting others and making friends, had very few friends to socialise with. Many requested the continuum of the planned social network schemes and increased staff contact. The quality of life seemed to be better for those who shared accommodation

3. Only one interviewee had literacy skills. Most interviewees commented on their lack of such skills. Some initiated enrollment in adult literacy classes but are not experiencing progress. Interviewees tended to blame their previous educational/training experiences for their lack of literacy skills.

4. Some interviewees recognized that they had a " handicap. " Others were very conscious of how they were looked at or related to by people in the community. This, however, did not inhibit them.

5. Interviewees were confident that if they had problems they could receive support from a staff member or other person with the responsibility to deal with the problem (i.e. bills, social welfare, etc.) They were also confident in their ability to deal with household problems such as burst pipes, fire, burglary, electricity strikes.

6. Most interviewees expressed the desire to be active and contribute to the lives of others. Examples: to do voluntary work; to give talks to people moving into community-based residences; to advise them and guide them; to work with the elderly; to join a club (badminton, crafts).

Some expressed the desire to move back to their town of origin or trace their roots. One person's goal was to find out who originally assessed him and labelled him.

Conclusion/Discussion

What have we learned from the interviewees regarding their quality of life using the principle of normalization as a point of reference?

I will attempt to draw some conclusions in as concise a manner as it is possible to do when deliberating on a subject of such human and social dimensions.

To do this, I will link our findings to John O'Brien's five major dimensions of the principles of normalization (9)

These are:

1. Community presence
2. Community participation
3. Skill enhancement
4. Image enhancement
5. Autonomy and empowerment.

While the first dimension—Community Presence—is evident, the second dimension—Community Participation—is not a reality for most interviewees.

The positive statements by interviewees regarding their coping and management skills when applied to daily responsibilities would indicate that the third dimension—Skill Enhancement—was positive. Image Enhancement, the fourth dimen-

sion, could be at risk for some Those who felt they were negatively perceived by others in the community may indeed be correct in their interpretation or they may project this perception from their past experiences. This survey, however, was not designed to address this dimension from the community's perception. Therefore, comparison and validation of perceptions is not possible. However, for some interviewees Image Enhancement would appear to be well-developed, given their wish to contribute to the welfare of others.

Finally, the dimension of Autonomy and Empowerment would seem to be positively reflected by the interviewees participating in the survey willingly and the fact that their views were sought and are regularly sought by staff. Their comments regarding their future plans and the need to have paid work, the latter being necessary for independence, also reflect the active promotion by the community-based residential service of healthy autonomy and empowerment.

Implications for the Future

There is no doubt that the philosophy and model of this community-based residential service has enabled the residents to experience many enriching opportunities. The personal achievements of some are a result of those experiences, coupled with the support provided to take the necessary risks. Social integration, if defined solely on the criteria which emphasizes relationships as of value, only if they are with non-disabled people and non-staff, does not at this point seem achievable for most of the people in these community-based residential services. Therefore, we need to examine our own values in this area. We should continue to foster the development of personal friendships, whether these be with people who are disabled, staff, befrienders or those members of our communities who do not present overt disabilities

I return to one of my issues noted at the beginning of my paper to emphasize this.

In our efforts to uphold the principles of normalization do we tend to deny the reality that people do indeed have differences, be they overtly or covertly manifested, and, if so, are we in danger of supporting the concept that to be different is not an acceptable social value?

The loneliness of individuals resulting from either their inability to initiate appropriate relationships and maintain friendships or their natural tendency to be alone is a critical factor for those responsible for the future development of community-based services.

We must also continue to provide the support necessary to enable people with learning disabilities to participate in the richness of community life at their own pace and in keeping with their wishes. At the same time, we have to be alert to any signs which might indicate to us as service providers that our community-based residences and our expectations of and for people with a learning disability are reflecting institutional attitudes and processes. This latter point has tremendous implications for staff empowerment through support networks, inservice training, and pre-or post-graduate training.

In conclusion, I believe that the interpretation and actualization of the principle of normalization in a qualitative way for people with learning difficulties is dependent on the interrelationships of each of the following factors:

— the values of service planners;

— the attitudes and skills of staff;

— the social conscience of the local community;

— the wishes and abilities of people with learning disabilities.

The following quote from the book *A Place of My Own*, by Margaret C. Flynn, 1989, encapsulizes the findings of our residents' survey and the future implications for service providers.

" We have been slow to realize that helping people settle into ordinary houses in ordinary streets does not of itself bring integration into the community or a high quality of

life We have to look beyond the bricks and mortar to ways of encouraging the development of social relationships in community settings. "

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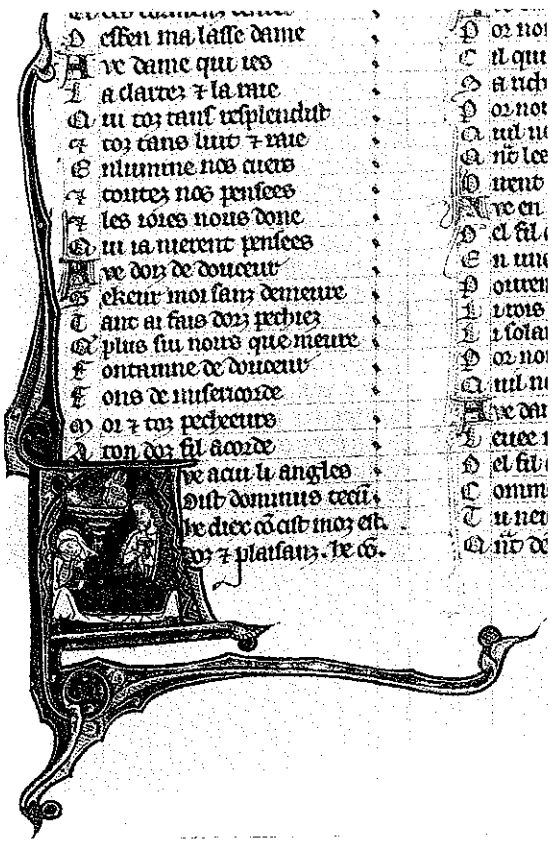


BONIFICAIO HONINGS

Disabled Persons and Love

Love

A book has recently appeared which presents the difference between the vision of certain educators and that of parents as regards the sexuality of people with, first and foremost, a mental handicap (1).

For the parents handicapped people live out their lives only in the sphere of affectivity, whilst for the educators this life should be lived also, and above all else, at the level of sexual pleasure. For the former, therefore, the handicapped person is more an asexualized person, whereas for the latter the handicapped person is a person who is strongly genitalized Naturally, the parents have always known that their children had sexual problems in general as well as genital problems in particular. Nevertheless, in these cases as well the question of sexual relations and conjugal unions was not raised. If, then, sexuality created difficulties from a genital point of view, the preventive solution lay in putting them inside institutions, depriving them of their freedom of movement, and compelling them to pass their lives in profound loneliness. However, the genitalizing vision of the educators is gaining ever more ground and gives rise to questions which oblige morality to look for balanced answers.

This paper is therefore organized along four axes: questions to be answered; criteria by which to decide; an attempt at evaluation; and certain answers.

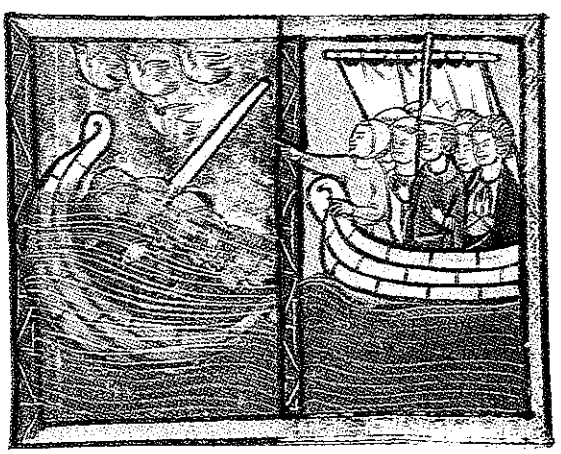
1. Questions to Be Answered

During the 1970's it was discovered that mentally handicapped people were capable of growth and development to such an extent that they could work and live as happily as other people In this way the theory of normalization was born. Or, to put it another way, the conviction that it was absolutely necessary to avoid segregation and that, therefore, handicapped people were to be treated as normal, precisely because they were capable of becoming normal. Naturally, this theory also, and above all else, included sexual life. Here is what a director of services for handicapped people has written: " We must treat the adult disabled person as an adult; we must accept him as having the characteristics of an adult, as an adult who is sexually developed. We often skirt this problem because of heavy prejudices that become stronger when we consider the sexual lives of handicapped and disabled people. In general, such people are normally developed in this area and have the right to a natural sexual life " (2). According to this idea of a right to the pleasure of genital activity, the personnel of institutions encouraged those that they looked after to engage in sexual relations. It should be noted

that " there is an insistence upon the importance of sexual activity in the human development of mentally handicapped men and women. It is necessary, therefore, to teach them and help them live out their sexuality to the full because they have a right to sexual pleasure; they should be helped to grow in this area " (3).

Nonetheless, and this is very significant for the subject at hand, these people are not allowed to have children, as if it were a serious crime for them (4). The theory of normalization, therefore, culminates in a clear " juridical yes " for genital needs and a clear " moral no " for biological fecundity. This is because, and I repeat the observation, the mentally handicapped person is said to have an inalienable right to sexual pleasure. According to this way of thinking, the handicapped person is allowed to live out his own sexuality as long as he makes use of artificial methods of contraception or undergoes sterilization or (in the case of a woman) goes so far as to voluntarily accept the interruption of a pregnancy. This *permissive* and *liberalizing* evaluation of self-and/or heterosexual satisfaction for handicapped people poses some inevitable questions concerning morality.

The first and most general is this: what should be done when a woman or a man who suffers from disabilities is attracted to a member of the opposite sex. Should they be hindered? Should what they do be prohibited? Should their wishes be complied with? In this case, what should the norm of their sexual behavior be? Genital pleasure? Unitive and fecund love? These questions refer back to other questions regarding the rights and duties of handicapped people in their intimate relationships and their entire love and life together. These and other questions, of a moral and juridical character, are already in themselves very serious and demanding, but they become even more so when we take into account another fact. It often happens that certain educational teams, under the pretext of acting for the good and the liberation of handicapped people—something they undoubtedly believe—encourage sexual relations without discrimination, regularly distributing the pill or practicing abortion when something goes wrong (5). In some countries there is discussion about the obligation of personnel to help handicapped people when these latter ask for auto- and/or heterosatisfaction. Obviously enough, all this takes place without any involvement of the conjugal bond or the duty to ensure that the intimate relationship is directed towards the possible creation of a new human life. According to a resolution of the European Parliament, there must be an opportunity for mentally handicapped people to be compelled to be sterilized (6). What has been asserted poses certain challenging questions to moral theology. These are questions which require replies given against a background of criteria oriented towards the humanization and the personalization of the sexual life of handicapped people themselves.



2. Criteria by Which to Decide

Every woman and every man has the fundamental, inalienable, and universal right to choose a partner with whom to share his or her whole life. Every human person, in that he is sexualized, has the original right to contract a marriage and to found his own family (7). I would like to point out immediately that this right derives from the will of God the Creator—that is to say it is immediately present in the very nature of the masculine or feminine being. No human law, therefore, whether secular or ecclesiastical, can remove this innate right from the heterosexual nature of every human being.

In the Book of Genesis it is written that God said: " Let us make man in our image, and after our likeness..... So God created man in his own image, in the image of God he created them; male and female he created them " (8). " Therefore a man leaves his father and his mother and cleaves to his wife, and they become one flesh " (9). Here we find, with all possible clarity, the juridical situation of every man and woman within the divine plan: God created woman for man and man for woman so that they would join together in an intimate sense as the highest, proper, and exclusive expression of their conjugal bond.

Without in any way wanting to undermine this natural-divine right

from an objective point of view, I would like, nevertheless, to point out immediately that marriage —and thus the will of God—involves notable consequences for the community environment, whether secular or ecclesial. As a result, the practice of sexuality, conceived by God as a natural right within married life, is subject to certain rules of both divine law and of ecclesial and secular law. This explains why human law, whether secular or ecclesial or both, makes clear the character of the divine law, both as regards the capacity of people to form a marriage and as regards the form in which their consensus must be expressed so that a conjugal bond can be established between a certain woman and a certain man (10). This power-duty of the relevant secular and ecclesial authorities comes from the social nature of marriage itself—this is because the conjugal bond not only creates new social relationships between the two partners but also gives rise to new relationships with the community of which they are a part. Those who freely unite themselves to one another not only create a relationship made up of a man and his wife but also create a specific and particular relationship as spouses in the eyes of the state and the Church. Marriage places the spouses, the state, and the Church in a context of reciprocal rights and duties. From this moral-juridical situation it follows that canon and/or civil law sometimes can and even must impede, if not prohibit, certain people from contracting a marriage. At a practical level this means that such people find themselves in circumstances or situations which are so special that they obstruct the very ends of marriage—that is to say, that they can prevent the satisfaction of its essential needs or work against its essential innate dignity. In order to explain these " prohibitive " circumstances to the full we must make reference to, and dwell upon, the concept of the marriage-pact or union-alliance.

Theological reflection today places emphasis on conjugal love, both as regards its unitive meaning and its procreational significance. Matrimonial love involves various properties such as, for example, that of being fully human, faithful, indissoluble, for the whole of one's life, fertile in both personal and trans-personal terms (11). At this juncture it is important to stress that conjugal love, because of its natural character, is oriented towards procreative and unitive meaning and therefore in order to be fulfilled must conserve this dual destination fully intact and unblemished (12). It is certainly true that " every love, by its very nature, is destined to spread itself and to expand. Conjugal love exemplifies this truth in special fashion. Interpersonal communion, which is a product of this love, pushes the spouses—themselves directed towards becoming one flesh—not only to give themselves to each other but as a single vital principle, through their role as mother and father, *together*, to prolong and project their love, their union, and their persons over time " (13).

Conjugal love thus becomes the principal and primary criterion by which to judge the answers which must be given to questions relating to the evaluation of morality in the sexual activity of handicapped people. If conjugal love requires, and requires because of its very nature, that its unitive meaning is not artificially divided from its procreative meaning, then for the life and sexual activity of the handicapped person as well, the same indivisibility remains a determining criterion.

The component elements of sexual love apply fully in the case of handicapped people: this love, by its very nature, and thus intrinsically, leads to perfective communion of the spouses and to their procreative co-action in the creation of children. This mutual perfecting and this common generative communion with God is strongly emphasized by the Fathers of Vatican II. They make clear that marriage is an intimate community of life ordered conjugal love, because of its natural orientation toward procreation and upbringing of children (14). Marriage calls people who marry to the daily creation and practice of a custom and communion for the whole of their lives—that is to say, a conjugal partnership which includes their entire existence in all the affective, sensitive, external, and internal aspects and components both of their persons—by which is meant their *being*

—and of what they do—by which is meant their *existence* (15).

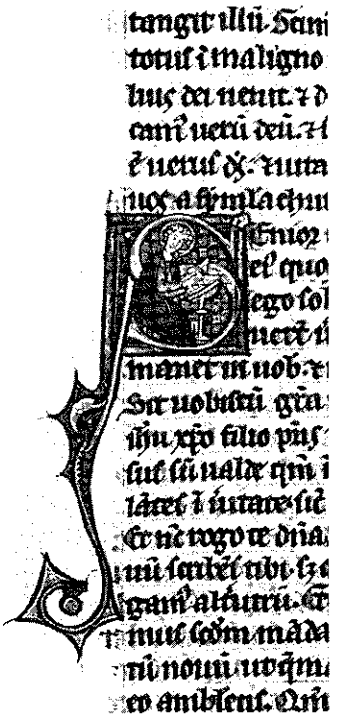
From what has previously been said it is clear that divine law, which is fundamental, universal, and inalienable, indubitably involves commitments which by their very nature condition its practical expression. In other words, when the Divine Creator established marriage he certainly wanted to give to a certain man and a certain woman the divine natural right to contract a marriage. But for that right to be exercised it is not enough to be female or male: for there to be the founding and the living out of the conjugal pact certain constituent and precise duties are required. For this reason, whoever is involved in the moral evaluation of the sexuality, the affective life, the sexual activity, and the marriage of handicapped people cannot depart from certain criteria which come from the divine will and are written both within the nature of man and of woman and in the very nature itself of the conjugal bond. I am thinking, at a specific level, of the criteria concerning the actual ability to begin a marriage, of the criteria which come from the juridical and moral ability to give life to a true conjugal partnership ordered and directed towards reciprocal perfection, and the creation and upbringing of children. However, it is in the light of these and other criteria that one must try to reach a balanced evaluation of the questions and answers not so much as regards natural divine law in itself but with reference to its responsible expression in matters relating to the sexual lives of people who are afflicted by disability.

3. An Attempt at Evaluation

I would like to say immediately that, as a general norm, no handicapped person should feel himself excluded from the divine right to marriage solely because he is disabled. " God wants to make married people a part of his love, of that personal love which He has for each one of us and as a result of which He calls upon them to help each other and to give themselves to one another so that they may achieve the fullness of their personal lives and of that love that He brings to humanity and to all his children and by which He hopes to multiply the children of men so as to render them participants in his life and in his eternal happiness ". (16) If God, therefore, as a matter of principle, does not want to exclude any man or woman from his personal love and thus calls upon them to reach together the fullness of their personal existence,—it follows that it is not for us to exclude them because they are (or one of them is) handicapped. By the simple fact that the handicapped person is male or female, God himself has included them in his general plan, in his project of love within humanity, which he wishes to carry out through marriage. No human authority can cancel or remove the divine call to take part in his love, precisely because He himself has placed it in the sexed nature of handicapped or disabled people.

However, as I have already made clear, this right has its own specific, particular, and exclusive dutird For this reason, even if the right to marriage as such is inviolable, its legitimate and valid expression depends upon a correspondence or otherwise to the inherent needs of its purpose and to the requirements of its dignity. Canon law, in this regard, requires that the juridical capacity is matched by a natural capacity or, to put it another way, that those who consent " have all the requisites that divine law and human law ask from unmarried people before they are able to contract a marriage " (17). It is not a question, therefore, of a denial of the objective right to marriage but of a declaration about the capacities and fitness (or otherwise) of unmarried people—that is to say, of their capacity or incapacity to exercise this right. For the people in question this means that a possible prohibition must be based solely upon the circumstances or the situations which bear upon the exercise of that right. I will now attempt to furnish certain examples.

There can be people who, because of their handicap, are examples of those who are incapable of performing acts which are ordered and directed towards the intimate communion of people and the procreation of a new human being.



The handicap thus renders the person the same as an impotent person and, consequently, incapable of corresponding to a constituent right-duty of marriage. A denial of marriage to these people with a disability does not limit their objective right. It does, however, regulate and coerce the exercise of that right because of the disqualifying circumstances. Canon 1035 makes clear in this regard that " everybody can contract a marriage as long as there is no impediment produced by canon, civil, human, or divine law, which both parties are obliged to obey in their celebration of marriage. " A handicap, to summarize, can be such as to disqualify the person from living a conjugal communion of life and love. I should point out that the judgement involved should also be subjected to the relevant anthropological science, and thus a moralist may not *a priori* prevent the marriage of a handicapped person.

The same evaluation applies to the marriage of people who, even though they are not obstructed in the exercise of their right to marriage by some kind of physical anomaly, are not able to marry because of a lack of the required knowledge and affective maturity. If, in general, nothing can be wanted before it is known, this is especially true in the case of marriage, where two people undertake to live, together, a life full of mutual unitive responsibility which is perfecting and procreative. There is a limit to knowledge, something that is indicated by canon 1082, par. 1: " For consent to marriage to exist it is necessary for the contracting parties, at the least, not to be ignorant of the fact that marriage is a permanent society between a man and a woman ordered and directed towards the creation of children. " " In contracting a marriage the spouses cannot be ignorant of the fact that they associate their persons and their activity to achieve the same end. For this reason they must know that marriage is a participation in the same destiny, in the same future, bound to each other in bad times and good " (18). As a result, in cases of mental handicap one must see whether the handicapped people have this minimum knowledge. I would like to observe that neither the law nor morality presumes its absence, precisely in order not to remove or limit, unjustly and wrongfully, the natural right of handicapped people to form a marriage.

Nevertheless, in this evaluation there is no room for compromise! Jean Vanier, the founder of L'Arca—the community where mentally handicapped people learn to live the existence of love—says, indeed, that one must have the courage to prohibit things. This is because one cannot allow a person to destroy himself or another person—this is true above all else when one is dealing with the active exercise of the sexuality of certain mentally handicapped people (19). At this point I would like to deal with certain answers to questions regarding the right of handicapped people to sexual pleasure.

4. Some Answers

The criteria which have been outlined above oblige everybody to approach the subject of the sexuality of handicapped people without a liberal and permissive mentality and, furthermore, without a dehumanizing or deprecating conceptualization. Certain specialists who help people who are very seriously handicapped at an intellectual level " think that handicapped people have especially strong sexual drives, even to the point of displaying an almost complete absence of inhibitions. They therefore believe that the sexuality of handicapped people is *genital* but also subject to partial drives (exhibitionism, homosexuality), and is consequently somewhat akin to that of animals. At a theoretical level, and in order to remain true to their liberal ideology, that argue that this sexuality is a right " (20). For no sexed person, therefore, not even for a handicapped person, can it be maintained that sexual desire is other than a blind impulse which brings with it the right to sexual pleasure. Experience teaches that " the sexual drive is a need for a relationship more than a desire or pleasure. It erupts, at times, when the person feels alone and anxious, but at a deeper level the person is looking for a friendship bond with somebody " (21). This relational charac-

ter of sexuality is no less true for handicapped people On the contrary. It is true that a handicapped person can convince himself only with difficulty that as a person he is loveable. He knows very well that he is judged, at an essential level, by exterior criteria, by criteria of physical, psychic, and mental normality or abnormality.

For this reason, to reduce the sexual drive of a handicapped person to a genital need to be satisfied, as something completely detached from the wish for a conjugal relationship, means to diminish even further, not only from an external perspective but also, and first and foremost, from an internal point of view To reduce the sexuality of a person with a disability only and exclusively to the genital sphere and to being a means of satisfying sexual drives without any relation to an interpersonal affective life or procreative fecundity, amounts to identifying it with that of an animal. I would argue that this statement is enough to unmask the falsehood of the " humanitarian " designation of the right to genitalized sexual pleasure. While it is declared to be a *juridical* conquest of liberation in relation to a *moral* taboo involving slavery, on closer inspection it turns out to be a deprecating depersonalization of the handicapped human being.

Morality, in the name of God, calls upon handicapped people as well to engage in a communion of life and love in which relationships of deep conjugal friendship constitute the essential criterion.

Given that the demonstrations of love of most handicapped people are of an affective character, they look for much more than a transient erotic emotion or a superficial orgiastic sensation Handicapped people want to link themselves to other people, create a true and authentic friendship which implies loyalty. The demonstrations of " innocent affection " or " genital sexuality " are two facets of the same need, of the same requirement: do you really love me and respect me? Do you really want to commit yourself to me? Does my life really have a meaning? Do I really have a place in your heart and in the human community? (22)

These questions posed by handicapped people not only do not find answers in the theories of liberalism or permissiveness, but are actually worsened Here is the answer to be given to all the questions which arise regarding the right to genital pleasure I am convinced that the problem of the sexuality of handicapped people can be solved at a pedagogic level. In the same way as every sexed person, every handicapped person must be helped to find, in gradual fashion, the unity of his own being and the integration of his own sexuality in a global vision of love, of friendship in general, and love of conjugal friendship in particular. This education requires the handicapped person—in that he is a sexed person—to learn " to love other people, to live out relationships with them of communion, of giving, of tenderness, of service, and of using their genital sexuality only in the realm of very specific alliance which is blessed by God " (23).

The divine right to sexual pleasure thus finds its full moral meaning in the interpersonal conjugal sphere—procreative and unitive love! Thus it is that the sexuality of the handicapped person as well, responds to the call of God—to achieve, in the midst of mankind, the fulfillment of his plan of love in Alliance Then, also, the handicapped person sacramentalizes, through his marriage, the mystery and the grandeur of the love between Christ and the Church (24).

In this way, handicapped people take part in the salvific love of Christ both as married people and as handicapped people. This is the message of comfort and hope that sexual morality offers to disabled people in matters relating to sexuality and love

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5. Cf JEAN VANIER, *Li Fece*. ., p. 165
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7. *Cf* Constituzione Pastorale Sulla Chiesa nel Mondo Contemporaneo, *Gaudium et Spes* n 26 and 87
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9. *Genesis*, 2, 24
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12. Cf PAUL VI, Enciclica *Humanae Vitae*, n 12; JOHN PAUL II, Esortazione Apostolica *Familiaris Consortio* n. 32
13. ANTONIO ABATE. *Il Matrimonio*. , p 17.
14. Cf *Gaudium et Spes*, n 48 and 50.
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16. PAUL VI, *Discorso al Centro Italiano Femminile*, 12 Feb. 1966, *AAS*, 58, 1966, pp. 220-221.
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18. ANTONIO ABATE, *Il Matrimonio*. ., p 44.
19. Cf JEAN VANIER, *Li Fece* , p 54
20. JEAN VANIER, *Li Fece* , p. 108
21. JEAN VANIER, *Li Fece* , p. 110
22. *Ibidem*, p. 111.
23. *Ibidem*, p. 112
24. I would like to reproduce here, as an illustration, no 8 of *Humanae Vitae*, which deals with this point: " Married life particularly reveals its true nature and nobility when we realize that it derives from God and finds its supreme origin in him who 'is Love, the Father 'from whom every family in heaven and earth is named ' " Marriage, then, is far from being the effect of chance or the result of the evolution of natural forces. It is in reality the wise and provident institution of God the Creator, whose purpose was to establish in man his loving design As a consequence, husband and wife, through that mutual gift of themselves, which is specific and exclusive to them alone, seek to develop the kind of personal union in which they complement one another in order to cooperate with God in the generation and education of new lives. Furthermore, the marriage of those who have been baptized is invested with the dignity of a sacramental sign of grace, for it represents the union of Christ and his Church "

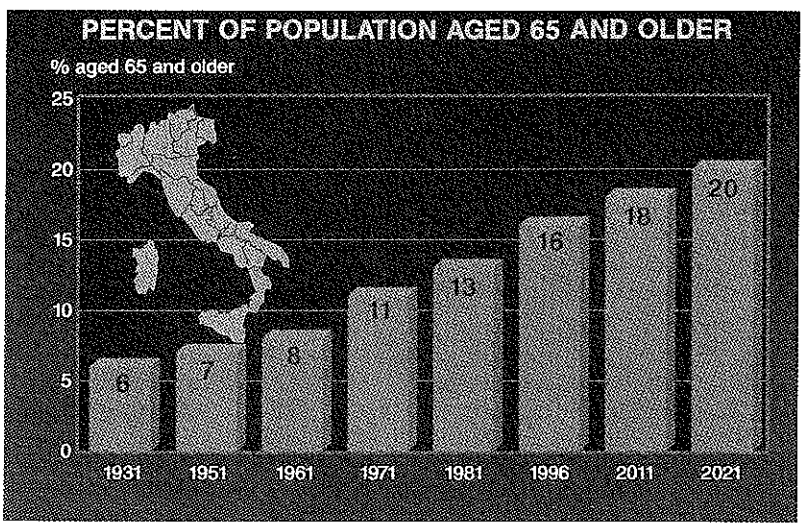
GAETANO CREPALDI-LEONARDO SARTORI

Environmental Conditions and Risk Factors in the Life of the Elderly

And God said: "Let us make man in our image, after our likeness; and let them have dominion over the fish of the sea, and over the birds of the air, and over the cattle, and over all the earth, and over every creeping thing that creeps upon the earth" (Gen 1:26-27).

Interaction with the environment has always characterized man's existence. This relationship, which was originally limited to the mere struggle for survival, has become gradually transformed into a complicated web of economic and social relationships. In the same way, the average life of the human being has grown longer—it was less than twenty years at the time of the first hominids; today it is roundabout sixty to seventy years. Old age, in this sense, is therefore a concept which by its nature is relative. Nevertheless, in the society of Neanderthal man, as amongst the skyscrapers of New York, factors such as malnutrition, loneliness, isolation, and illness have always characterized the experience of the elderly parts of the population.

Indeed, notwithstanding the undeniable advances which have been made in many other areas of civil society, care of the elderly has not yet reached a satisfactory solution beyond that provided within a narrow family environment. Moreover, recent phenomena such as urbanization and economic development along industrial lines, which favor the disintegration of the family nucleus, have caused a progressive increase in the number of people who live alone. At the present time, 30% of people over the age of seventy-five live alone, while 55% of people over sixty-five



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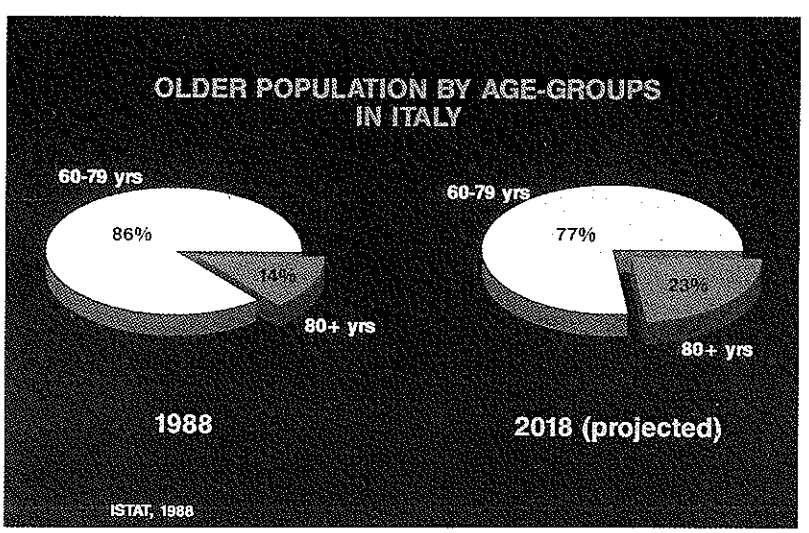

Fig. 2

who do not live alone live in the company of the same age.

Demographic data further confirm the character of the problem: in Italy life expectancy at birth is about eighty years for women and seventy years for men. In our country demographic growth has by now reached a post-transitional phase characterized by low mortality and low fertility. Since 1931 the average lifespan has increased by sixteen years in the case of men and twenty years in the case of women. The proportion of the population of sixty-five and over was a little over 5% in 1931; it will reach the impressive figure of 20% by the year 2021 (see Fig. 1) This elderly population will, however, experience a gradual further ageing as a result of which people over eighty, who in 1988 represented 14% of the people over sixty, by the year 2018 will constitute 23% of the whole category (see Fig.2).

The incidence of illness will also increase with age. Many of these illnesses will be chronic, and as a result the elderly person will display a polypathological condition. In such a context not only life expectancy but above all active life expectancy will become more important. In addition, there is the risk—at least in the most advanced societies—that an ever greater number of illnesses will be nursed rather than treated. This will have very great consequences for the entire economic and social complex.

Many forms of infirmity are not substantially different in the case of elderly people in comparison to the normal adult. If by " disability " we nonetheless mean any limitation or loss of ability to carry out an activity in line with what is considered normal, the term acquires in the case of the elderly person a meaning all its own. The functional state of the elderly person is conditioned, indeed, by a whole series of factors which are not only of a medical character. They are affective, environmental, social, and economic. In this context, illnesses in themselves do not necessarily cause invalidism. They can interfere notably with the ability of the person to manage his own life and thus give rise to that special form of invalidism which is defined as " nonself-sufficiency " in the geriatric field. " Nonself-sufficiency " is defined as being an inability to perform certain basic functions in independent fashion such as: feeding oneself, washing oneself, getting dressed, moving around within the home, managing the physical functions, looking after the home. In the case of elderly people who live alone, self-sufficiency further requires the ability to carry out certain " instrumental functions, " such as writing, reading, cooking, cleaning the home, going upstairs, looking after money, organizing the shopping and washing, telephoning, travelling, and dealing with medicines. A large number of these " nonself-sufficient " elderly people end up by being institutionalized.

Furthermore, the number of elderly people who are not self-sufficient increases with age. The ISTAT figures for 1988 show, indeed, that the proportion of people in need of help in carrying out daily activities goes rapidly from 7% amongst the young-old (65-74 years old) to 40% amongst the old-old (75 and over) (see Fig.3).

Arthrosis, cataracts, cardiopathy, diabetes, tumors, ictus, osteoporosis, and fractures connected with osteoporosis are the illnesses and infirmities which most often cause a loss of self-sufficiency in the case of elderly people. Certain illnesses such as dementia, a paradigmatic example, do not find a place in this subjective list because the patient is not aware of his condition.

Despite their undoubted relevance certain special conditions such as mental alterations, apathy, muscular weakness, articular stiffening, loss of balance, and so forth are, on the contrary, systematically ignored, with the result that the presence of " nonself-sufficiency " in the elderly person is underestimated.

The identification of the possible causes of nonself-sufficiency can lead, in certain cases, to the creation of suitable prevention. This, in turn, can be of a *primary* kind which eliminates specific risk factors; of a *secondary* kind which essentially involves early diagnosis; or, finally, of a *tertiary* kind which aims at reducing the presence of possible complications.

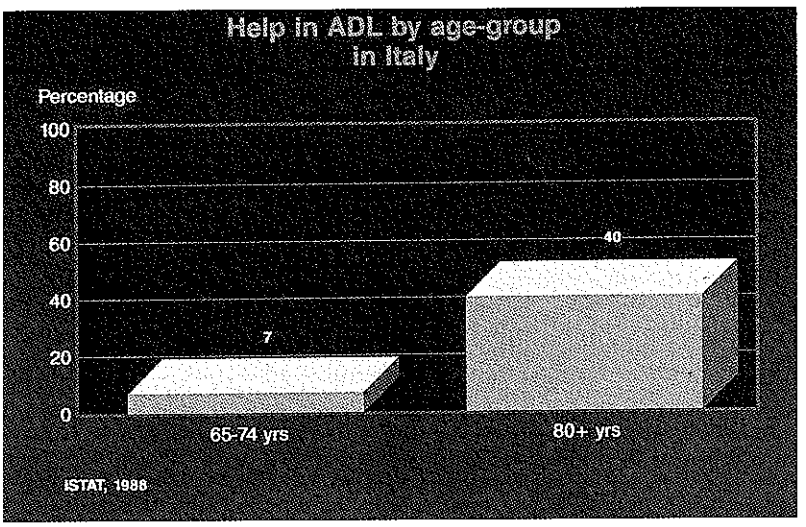

Fig. 3

The enormity of the problem does not allow a complete description of its character. The causal factors vary and a nosographical classification is therefore necessarily approximate (see Tab 1). We will limit ourselves, here, to the rapid presentation of certain paradigmatic examples.

Dementia is today the principle cause of " nonself-sufficiency " in the elderly population (44% of cases). By dementia is meant a disease of the central nervous system which causes a gradual loss of the mental faculties (memory, learning, attention, judgement) with interference of all aspects of thought in its most advanced stages. A recent study of the Italian Group for the Pharmaco-Vigilance of the

Elderly which is based upon 10,946 people admitted to 45 hospital centers, estimates that about 3% of the population over sixty-five years of age is affected by disabling forms of dementia. Of these, over 50% are afflicted by Alzheimer's disease and about 20% by " multi-infarctual " dementia. At the outset, the different forms of dementia can respond to empirical measures such as sensorial stimulation, physical exercise, the maintenance of the original domestic furniture, but the *exitus*, nonetheless, inevitably arrives in a relatively short period of time. Even if the patients are not aware of their state, the effects of this disease on those members of their families who live with them can be destructive.

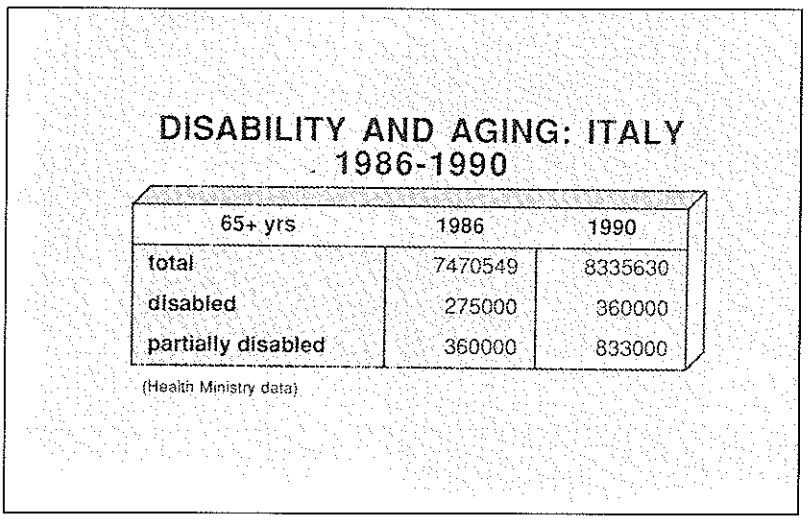

Fig. 4

Alcoholism, even though it represents a category all its own, is often confused with senile dementia. Its consequences (such as acceleration of the ageing processes, falls, malnutrition, and morbidity) are more important in the old person than the young person, first and foremost because it compromises independence and as a result is a frequent cause of institutionalization.

Within the category of *muscular-skeletal diseases* arthrosis-induced degeneration and fractures connected with osteoporosis are those which have a bad effect on the quality of life of the elderly person to the greatest extent. For example, the fracture of the femur alone leads, in 40% of cases, to a serious undermining of levels of self-sufficiency. Early diagnosis, however, can permit a reasonably effective measure of prevention.

Urinary incontinence, whose consequences range from simple physical inconvenience to a real and authentic social marginalization, is another common risk factor working for nonself-sufficiency in the elderly population. The previously cited study of the Italian Group of Pharmaco-Vigilance for the Elderly shows, indeed, how the incidence rate of the phenomenon passes from 10% of the population of those of sixty and over to 20% in the eighty and over band. Urinary incontinence is not, however, inevitable. In secondary cases of infections to the urinary tracts and in certain confusional states it is possible to carry out effective treatment through the use of certain medicines or drugs.

Sensorial modifications in the elderly person constitute another group of risk factors. *Sight disturbances* are usually a matter of the loss of an accommodation ability, night vision, and visual sharpness. Secondary alterations caused by well-defined pathologies such as diabetes, hypertension, and arteriosclerosis can, however, be prevented though treatment of the primary illness. Special devices such as good lighting and sufficiently large letters in written material can prove to be useful.

Auditory ability as well, beginning at fifty, undergoes a slow deterioration. In Italy, 62% of cases of deafness are to be found in the population over sixty-five years of age. The individual who is not able to communicate has a socialization level which is markedly reduced. He becomes isolated in the external world and, in extreme cases, there can be serious impairment of his intellectual functions. An acoustic prothesis is often an effective solution to the problem.

In this context alterations in the *condition of teeth* are often ignored. Contrary to common suppositions, edentulia is not an inevitable feature of old age. The role that the mouth plays with regard to correct phonation, diet, and aesthetic appearance is in itself important enough to require preventive action which, in this specific instance, can be extremely effective and useful.

In Italy about 15% of the elderly male population and about 30% of the elderly female population is affected by *depression*. This illness is characterized by a reduction of the quality of mood whose symptoms are loss of appetite, loss of weight, insomnia, tiredness, asthenia, irritability, intolerance, melancholy, lack of interest, anxiety, and lack of self-esteem. Illnesses, changes in social status, and loss of loved ones can be the precipitating causes. The symptomatology is often unclear and it is difficult to distinguish behavioral changes due to old age from conditions which are clearly of a pathological nature. Only one elderly person out of ten is treated correctly. If not properly dealt with, depression can lead to suicide. The incidence of suicide, naturally enough, increases with age.

The population over sixty years of age usually uses a quantity of medicines which is twice that of the rest of the population. Given that reactions to medicines are proportional to the number of medicines taken, it is not surprising that hospital admissions caused by *iatrogenic pathologies* are fifteen times more common amongst the elderly. Adverse reactions range from simple headaches to more complicated and damaging organic phenomena such as hypotension, dysiony, A-V blocks, mental confusion, hypoglycemia, hemorrhages, and coma. An extremely effective form of preven-

tion can take the form of only taking medicines which are strictly necessary; obeying to the full the dosage prescribed; avoiding re-using used medicines; keeping the medicines in the right way; or entrusting control of the medicine to another member of the family.

With reference to disability and self-sufficiency we must discuss the special role played by the *economic resources* of the subject. Poverty is often accompanied by ignorance, loneliness, and depression. It can also influence the physical health of the elderly person: malnutrition, bad living conditions, reduced ability to cope with things to such an extent that the " very poor " fall ill more easily and have a higher level of impairment of their functional state than those of their same age group who, on the contrary, do not suffer from being very poor.

One can well understand how a demographic increase in the elderly population will involve a corresponding increase in the number of non-self-sufficient elderly people (see Fig. 4). The concomitant disintegration of the family nucleus will, in addition, have the effect of overloading the *social and health care systems* to an excessive extent. The elderly patient today constitutes the greatest user of medicines and clinics. In Italy 70% of those admitted to hospital are drawn from the sixty and over age group, not to speak of the fact that 10% of the female population and 5% of the male population over the age of eighty-five are institutionalized. The problem is compounded by a fall in the birth rate. Between 1980 and 1990 the index of the ageing of the population—the relationship between the number of people of sixty-five and over and a hundred people between zero and fourteen years of age—has indeed passed from 60.2 to 91.2. It is not, therefore, difficult to assume that the index of social burden, calculated with reference to the relationship between the number of elderly people and a hundred people of working age (presently 21.5), will experience an early consensual increase.

In conclusion, we would like to emphasize and make clear that the ageing of the population is not a problem which afflicts only the industrialized countries—in 2020 75% of the elderly population will, in fact, live in developing countries. The solution to the problem is by no means simple. Elderly people, especially if they are disabled, have always been a group at risk. Almost two thousand years ago Juvenal wrote: *Sed morte magis metuenda senectus!*—old age must be feared more than death! (*Sat.* 11, 45). Unfortunately, this aphorism is today more apt than ever!

PREVALENCE OF COMMON SELF-REPORTED CONDITIONS IN PEOPLE 60 YEARS OF AGE OR OLDER.

CONDITIONS	% POPULATION
Arthritis	49.0
Hypertension	41.8
Cataracts	19.9
Heart disease	14.0
Varicose veins	9.9
Diabetes	9.5
Cancer	6.6
Osteoporosis or hip fracture	5.5
Stroke	5.4

Tab. 1

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Spirituality for an Endless Freshness of Life

1. The Right of the Handicapped Person to Holiness

The Right to Citizenship of handicapped people within society and the Church has become increasingly upheld and enforced over recent years. In particular, in the ecclesial world this right of citizenship has met with affirmation, first and foremost, in the catechism, the celebration of the sacraments with handicapped people, and the commitment to favor and foster their spiritual education and development. But the response to this right is not yet complete.

This is because we must achieve the promotion and upholding of the right of citizenship of disabled people to the life of holiness within the Church, and to the right of " life according to the spirit, " which, by its nature, is dynamically oriented to the perfection of charity. This is a right which is still denied, wrongly recognized, doubted, or, whatever the case may be, not sufficiently appreciated.

The right of the disabled person to be seen as capable of progress in his spiritual life and to be helped in his pathway to holiness finds its roots not so much in a human recognition—necessary though that may be—as in the plan itself of God which was revealed to us in Jesus Christ. Two words of the Gospel serve as radical and decisive proof of this right. The first is the missionary command of God: " Go into all the world and preach the Gospel to the whole creation " (*Mk* 16:15). In that phrase, " the whole creation ", we find the categorical affirmation that nobody is excluded from the preaching of the Gospel which the Lord Jesus entrusts to the Church. And, at a positive level, there is the statement that each person in his practical conditions of life, and therefore in his uniqueness and irreplaceable singularity, is called to the Gospel, or rather to receive the gift of salvation as a free participation in the life itself of God.

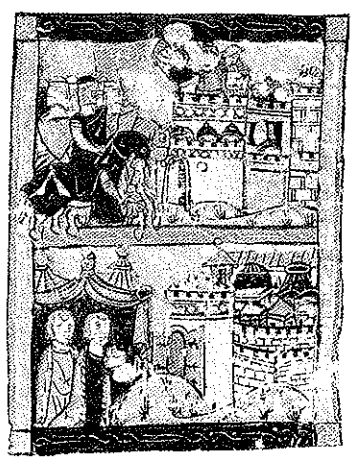
The second word is the appeal of Jesus: " You, therefore, must be perfect, as your heavenly Father is perfect " (*Mt* 5:48). This is an appeal made without distinction to everybody. There is no exclusion or discrimination involved in this appeal. It is directed, therefore, to the disabled as well. And to whom did the Lord Jesus address his call for perfection if not to those people—those poor people—amongst whom there were so many ill people and so many people afflicted by handicap?

It is certainly true that spiritual life, the pathway to holiness, is a gift from God, a gift which is totally free and for which no payment is required. But man is called upon to respond to the divine gift, to give an authentically human answer, made, therefore, of conscience and freedom. Holiness, with regard to man, constitutes the complete and perfect response to the gift of God.

2. Can the Disabled Person " Exercise " the Right to Holiness?

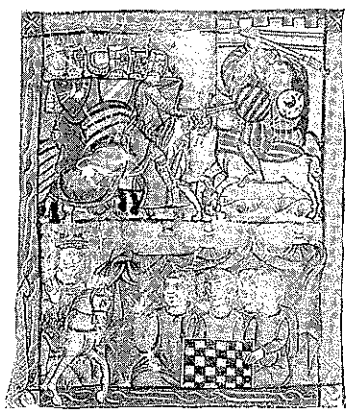
There thus arises the inevitable question: " One can, and indeed, one must, uphold the right to a spiritual life and to holiness on the part of disabled people as well. But is the disabled person, and, above all, the mentally and psychically disabled person, effectively able to exercise this right, to give, therefore, a complete and perfect answer to the call of God? This question is a real and authentic challenge to what is the usual mentality, a mentality which is often marked by prejudices or, in any event, by a need for more precise knowledge and information.

Rationalist " enlightenment " has no minor influence on the usual mentality. It interprets and understands man in a reductionist, indeed, distorted, way. Man is understood, almost exclusively, in terms of intellectuality, as if man were definable in terms of his intelli-



gence and its practical expression and as if human progress were the same as intellectual progress. But does man know things only through his mind and his intelligence, or does he also know things, and perhaps to no lesser extent, with his heart and through love?

H. Bissonnier writes: " It is not only through intelligence... that our relationship with God is formed. We are hyper-cerebral creatures, we are 'great heads.' " It is like this: man is evaluated only by what he has in his head, and it is forgotten that man is also, and perhaps to a greater extent, heart. The criteria of God, fortunately enough, are different from our own. Saint John of the Cross reminded us: " At the sunset of our lives we will be judged in love. " Now, are those that are not brilliant in intellectual terms those that love the most? Many people who are very seriously mentally handicapped are capable of extraordinary acts of love, and of authentic love. And, furthermore, whatever the case may be, it is with all our human existence, from our head to our toes, that we are called to go to God, to meet God, to be heard, to be transformed by this God of Love, who, according to the words of the Apostle Peter, " wants us to share in his divine nature "



(" *Il diritto allo spirituale per un'educazione integrale*, " in Integralità dell'educazione e diritto allo spirituale, Rome, 1991, pp 50-51)

The usual mentality, above all in a context dominated by technology, is conditioned, in addition, by positivism. This philosophy believes that what is real is that which is attainable through experience and is the object of material verification. But is man really reducible to his biophysical or psychic elements? Does he not also have other elements of a spiritual nature? And with what right can one seek to cover the entire knowledge of man through experimental science alone?

The truth is that man is a mystery. He is a mystery in the original sense of being a creature who takes part in the mystery *par excellence*, who is God. He is a mystery for the further reason that man is not able to read himself in the totality of his being. This is because the real space occupied by his knowledge, his freedom, and his responsibility is not always fully measurable or capable of being deciphered. I think that it is possible to make a parallel between so-called " negative theology, " by which God is more the things that are not known than the things that are known, with " negative anthropology ": with man as well the things that are not known are much greater than those that are known.

After this dual clarification on the understanding of man beginning with his totality, and therefore with intelligence and love, with experience and " mystery, " we will consider the disabled person—his spiritual life and the call he receives to obtain holiness.

3. Man: A Being of Communion and Giving

One must see the disabled person as God sees him. And God sees man, every man, and therefore also the disabled man, in his most profound and truest reality—man is the living image of God the Creator and Redeemer. With the biblical term " image " there is indicated in a simple and surprising way the extraordinary richness that God wants to give to every human being: this richness is to be found in the fact that every man is a person and is a person because he is essentially relationality. He is an I open to you, a being called to enter into communion with others and to give himself to others.

Communion and giving are the essential and structural innate features of every human being—they define his identity (cf., *Gaudium et Spes*, no. 24). As the Holy Father John Paul II said when giving an audience on 9 January 1980: " A gift reveals, so to speak, a special characteristic of personal existence, indeed, of the very essence of the person. When God Yahweh says that 'it is not good that man should be alone' (*Gn* 2:18), he makes clear that on his own man cannot thoroughly fulfill his essence. He fulfills it only when existing 'with someone,' and at an even deeper and more complete level, when existing 'for someone.' "

Man enters into communion and gives himself to others: to other men and ultimately to God himself. But God is not only at the end, he is also at the origins: he is the constitutive and dynamic beginning of the relationality which defines man; he is that which renders him possible, real, and realizable. Man is capable of entering into communion with others and giving himself to others because he is the living end of a communion and giving which come from God himself. We might say that man is the " sacrament of God, " or rather the personal living sign of God, who enters into communion and gives himself to man.

This emerges " at the beginning, " with the creative act of God: the creation, as a step from nothing to being, is the testimony of this God who involves himself with man and gives himself to man, making him in his image and likeness. And what emerges " at the beginning " finds its supreme expression in Jesus Christ, in the Son of God made man. It is the human flesh, that which he took from the breast of a woman, Mary, which is the strongest, incontrovertible, and indestructible proof of the fact that God enters into communion with man and gives himself to man. More precisely, it is upon the cross, in the crucified flesh, in the body given and the blood spilt of Christ

that the new and eternal Alliance is formed and there is proclaimed to the whole world that summit to which are affixed the solidarity of God with man and the gift of love from God to man.

4. Disabled Man's " Gift "

It is now necessary to apply what has been said about the identity of the human being to the disabled person in particular.

But do we really have to engage in such an operation? Do we not run the risk of taking part, however involuntarily, in doubt about the full and perfect personal dignity of the disabled person, especially of the disabled person who is in a particularly serious mental and psychic condition?

In reality, this application is not only legitimate, it is also necessary: it helps us to perceive with greater clarity certain fundamental characteristics of man as such. The disabled person, also, precisely because he is a man, finds his " truth " in being in communion with others and in being called to give himself to others. There is no doubt about the existence of a factual communion of the disabled person with others. The doubt could only arise as regards his capacity for a real and authentic giving of himself to others.

But if the handicapped person is a human being, then without a shadow of a doubt—even if in his own way (that is, in an original manner not fully grasped by us)—he is not only with others but he is able to live out his fundamental vocation, which is that of offering himself to others, to give himself to others. In a word, to love (cf. *Familiaris Consortio*, no. 11). And who is so foolish as not to perceive the contribution of authentic and profound " humanization " that the disabled person offers to our social life, something which is threatened and disfigured every day by the idols of having, of power, and of pleasure?

It should be made clear, however, that communion and giving on the part of people act according to reciprocity—this is their logic and their law of life. Each of us is the end and the beginning of a relation—one receives and gives, gives and receives. As a result, given that the disabled person is with others and for others, so others are in communion with the disabled person and are called upon to give themselves to him. They are to do this with greater urgency and with a vocation that displays greater commitment. The logic and the law of reciprocity seem to weigh upon, and lean more towards, the non-handicapped.

Indeed, the more, so to speak, the humanity of the person is naked—and this could especially be the case of a mentally disabled person—then the deeper must be the communion of others, the more intense must be the giving of others to the disabled person so as to dress and render beautiful this naked humanity of his. And without forgetting the very great need of handicapped people to be welcomed and loved. But we must reach the heart of the relationality which is typical of every man, the communion and the gift of God himself in favor of man.

The true greatness of man is not so much in his communion and his gift of love to his fellow men. Nor is it in the even more meaningful fact that man enters into communion with God and gives himself to God. It is, rather, in the overwhelming fact that God himself engages in solidarity with man and gives himself to him; he makes him an alive and palpitating end of his communion and his love of giving. This is a communion and a giving which are in essence free—man has no right in the matter. But precisely for this reason there emerges in illuminating fashion the ineffable coming down of God to man, an embrace of the love of God with man himself.

5. The Light of Eternity on the Present Day

This is an " embrace " which is already expressed in time, but it is also oriented by its nature to realize itself in eternity. If every Christian life finds in " eternal life " the end and therefore the yardstick of value of every moment and situation of present-day time, this finds its most illuminating confirmation—I am

speaking here above all of that light that only faith gives—in the Christian life of the disabled person: the ultimate sense of his " body ", which is to a greater or lesser extent tried, can find itself in the " glorious body, " that, precisely, of the condition of " being always with the Lord " (*1 Th* 4:17). The apostle Paul reminds us of this: " What is sown is perishable, what is raised is imperishable. It is sown in dishonor; it is raised in glory. It is sown in weakness; it is raised in power. It is sown a physical body; it is raised a spiritual body " (*1 Co* 15:42-44). In the same way as the ultimate meaning of his " spirit, " which is to a greater or lesser extent free, can find itself only in the vision, in the love, and in the blessedness of heaven. However, as Paul VI said, " where this conscious adherence is not possible, the gift of divine life is called to enclose itself in him who was its beneficiary, in the beatific vision. "

The light of the resurrection is able to illuminate the meaning of suffering undergone at the present, the suffering connected with mental and physical handicap as well. And this applies to everybody. During the synod on the lay faithful of 1987 a handicapped person, during a speech to the synod assembly, declared: " It is very important to point out the fact that Christians who live in conditions of illness, of pain, and old age are not invited by God merely to unite their own pain with that of the Passion of Christ but also to have within themselves and transmit to others the force of renewal and the joy of the risen Christ (cf. *Col* 4:10-11; *1 Pt* 4:13; *Rm* 8:18 ff.) " (*Propositio*, 53, in *Christifideles Laici*, n. 53).

If only briefly, it is not possible to ignore the essential ecclesial dimension of the pathway of disabled people towards Christian holiness. This means that each holiness is a participation of the holiness of the Church, both in the sense that the Church is the mother of holiness as regards every believer and in the sense that the holiness of each believer is a precious thing, a spiritual enrichment of the whole Church. Saint Lawrence presented the poor as the " treasure of the Church. " Saint Ambrose made the following observation: " And they are truly a treasure, those in whom Christ resides.... What greater treasure has Christ than those in whom he loves to place himself? " They are also a " treasure " in the specific sense that they enrich the Church, and reveal her holiness and cause it to grow

Conclusion

I hope it is fitting to conclude this paper with a simple and yet profound summary which has the advantage of being suggested by Marie Hélène Mathieu, the co-founder of the movement " Faith and Light ": " God is love. God created us, each of us, in his image, so as to be a person capable, in Him, of relations of love—or more precisely of communion.... It is with the heart, this very center of our person, that we can enter into this communion.... We believe that the mentally handicapped person, even if he is limited in his intelligence, in his independence, in his reasoning and abstract thought abilities, is not limited in his heart. God created him in his image. He has loved him as he has loved each of us. He is able to respond to love, to fall into line with God's wishes as they apply to him " (" La Persona Handicappata Mentale e il 'Suo' Dio, " in *op. cit.*, p. 118).

This is nothing other than the " secret, " the beginning, and the force of the pathway towards holiness, towards an " eternal freshness of life. "

Archbishop DIONIGI TETTAMANZI
General Secretary of the Italian Bishops' Conference

EUGENIA KOGAN

Cerebral Ictus and Its Consequences

1. Introduction

Cerebral ictus (or " stroke ") is an old-fashioned term which is used for the designation of disorders of the cerebral or marrow circulation with the acute onset of a focal neurological syndrome and an anatomical destruction of the neural tissue

Cerebral ictus is one of the most serious and widespread diseases of the brain. It is of great significance because of its high frequency, death, and invalidation rates. The situation is aggravated by the fact that the majority of patients with stroke are efficient persons. The death-rate from cerebral ictus occupies second or third place among all causes of death. The frequency of death from cerebral ictus is about 40% in the majority of countries, including Russia, while the greater part of the survivors become persons with disabilities in society

2. Classification and Morphology

Cerebral ictus usually develops in persons with cerebral forms of atherosclerosis and/or hypertention and ocasionally cerebral vascular malformations. Other types of destructive lesions such as tumor or abscess may also manifest sometimes with a rapid onset, resembling " stroke. "

There are three major categories of cerebrovascular diseases with the clinical symptomatology of cerebral ictus: cerebral infarctions, intracranial hemorrhages, and vascular encephalopathies.

Cerebral infarction is the most frequent form of cerebral ictus. It

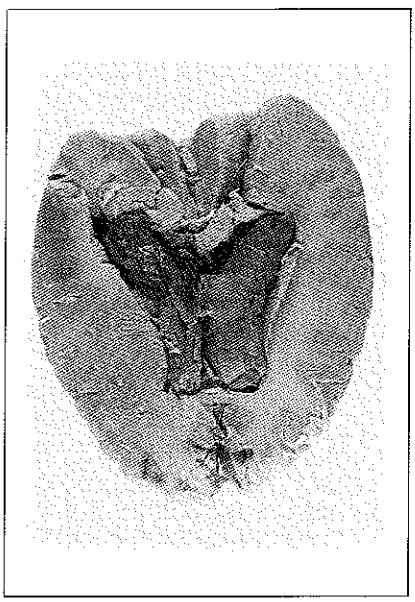


Fig. 1. The anemic infarction; Large discolored region in the middle of the hemisphere.

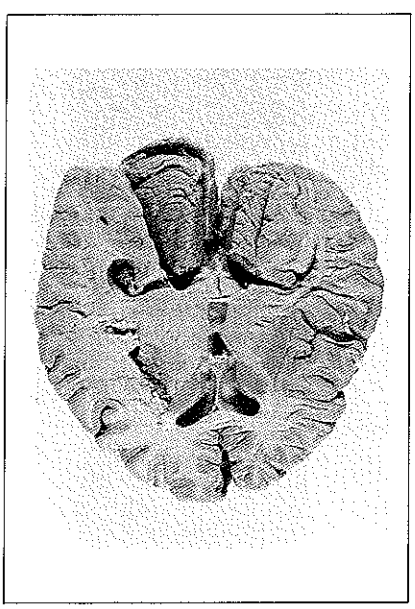


Fig. 2. Massive hypertensive hemorrhage rupturing into lateral ventricle

may be caused by local vascular thrombotic, embolic, or spastic occlusion; the compression of vessels against dural folds during herniations; severe atherosclerotic stenosis of vessels combined with nonefficient collateral circulation or reduction of perfusion pressure. There are three forms of cerebral infarctions: anemic (most frequent Fig. 1), hemorrhagic (uncommon), and mixed.

Intracranial hemorrhages develop usually from rupture of vascular aneurisms after hypertension or vascular malformations. Subdural hematomas result from the rupture of bridging veins after traumas. There are three forms of intracranial hemorrhages: intracerebral, subarachnoid, and subdural (Fig. 2).

Vascular encephalopathies include two forms of the disease: atherosclerotic and hypertensive. Pathological lesions are small in size, localize usually in the white substance of the deep areas of the brain and are represented by small lacunar necroses, hemorrhages, cysts, and glial scars.

The clinical expression of cerebral ictus reflects its pathological severity.

Consequences of cerebral ictus depend on the size of the necrosis or the hemorrhage, their localization, duration of ischemia, course and severity of atherosclerosis or hypertension, and the time of the beginning of special treatment. About 40% of patients with cerebral ictus die because of the destruction of vital neural centers and routes, severe brain edema, or haematic effusion into cerebral ventricles (Fig. 2).

Those who survive the acute phase of the disease become the persons with disabilities in society because neurons do not regenerate in the regions of necrosis. Saved neurons can usually only partly compensate for the functions of dead ones. The processes of resolution lead to the cerebral cyst (Fig. 3) or the glial scar (Fig. 4) formation.

Progress in the proplylaxis and treatment of cerebral ictus is based on the discovery of new genetic and molecular mechanisms in its development. The significance of the free radical lipid peroxidation and the activation of the immediate-early genes in alteration and regeneration of neural tissue after cerebral ictus is obvious.

3. Free Radical Lipid Peroxidation

The alteration of the neurons in cerebral ictus is ischemic in nature and is connected with the oxygen deficit. The mechanism of the ischemic alteration of the cells is based on free radical lipid peroxidation.

Why does the process of lipid peroxidation have great significance for cells? It is so because lipids are one of the main compounds of cell membrane organells. They influence membrane permeability and enzyme's activity. They are the source of energy and necessary synthesis of many biologically active substances. Free radical lipid peroxidation takes place when lipids interact with oxygen, especially its active forms. Peroxides and peroxide lipid radicals are generated. They are rich in oxygen and very toxic for cells.

It seems unbelievable that lipid peroxidation can increase in ischemic tissues, where the oxygen supply is reduced. But, as established in experiments on animals with ischemia, amplification of lipid peroxidation may occur after the beginning of the ischemia. The rate of lipid peroxidation becomes maximum till the third day of experiments with mycardial ischemia and is normal at the thirtieth day, at the time when a scar is formed in the region of the ischemic necrosis.

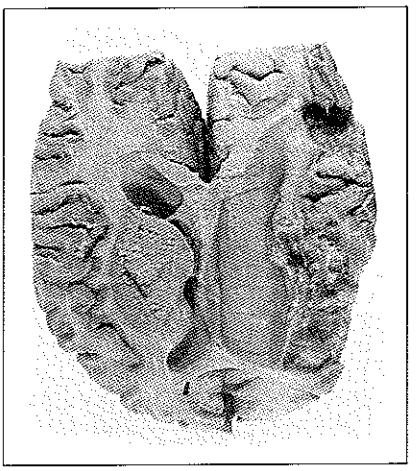


Fig. 3a. Old cystic infarcts in both hemispheres: *a* - grossly.

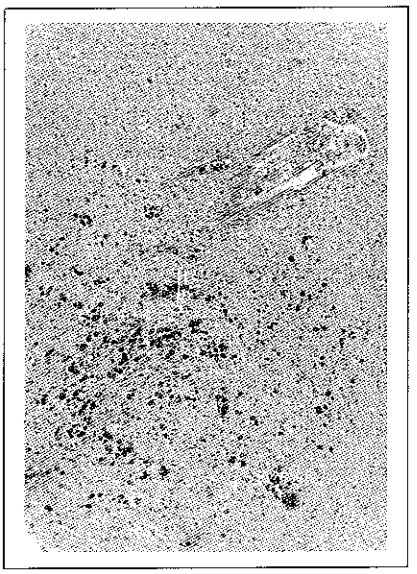


Fig. 3b. Old cystic infarcts in both hemispheres: *b* - histologically, X250.

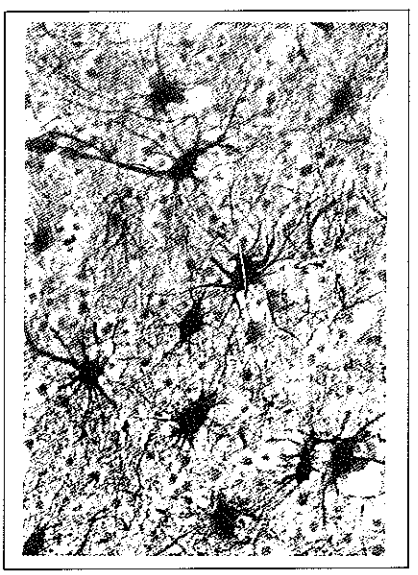


Fig. 4a. Glial scar in the region of the hemorrhage (*a*) with proliferation of astrocytes.

The question about the sources of oxygen in the region of the ischemia remains unsolved. One can speculate that there are different sources of oxygen: oxygen may come from the erythrocytes of arterial blood of the border zone, which separates ischemic and normal tissues. This zone has intensive vascularization and oxygen supply; another source of oxygen involves fagocytes, that concentrate in the border zone and can generate active forms of oxygen that are a powerful stimulator of lipid peroxidation. The lipid peroxidation may be stimulated also by hormone adrenaline, which usually comes into the region of ischemia in overdoses. Free radical lipid peroxidation leads to the damage of cell membranes, especially mitochondrial, and causes the death of cells.

It is hypothesized that the ischemic cerebrum can register lipid peroxidation by itself. The majority of people who have suffered cerebral ictus and been in the state of clinical death describe the unexplained sensation of light at the end of a dark tunnel. R. Moudi was one of the first who tried to explain this sensation by the deficit of oxygen in the dying cerebrum. Now we can assume that after the blood supply to the cerebrum is stopped and the deficite of oxygen takes place, the intensive lipid peroxidation with phosphorescence of the daylight begins in all neural cells and in cells of the eye retina as well. These cells have photoreceptors and transmit signals to the optic centers of the brain, which leads to the sensation of the light.

4. Immediate-Early Genes

Another new phenomenon which is of great significance at cerebral ictus is the activation of immediate-early genes. This group includes genes of the Fos-, Jun- and Myc-families and plays an important role in the reactions of cells to different mitogenic stimuli that induce mitosis and cell transformation. These genes are activated at tumor growth and are also called cell oncogenes. We investigated the expression of c-fos and jun in tumors and found, for example, the activation of them (Fig. 5) at the

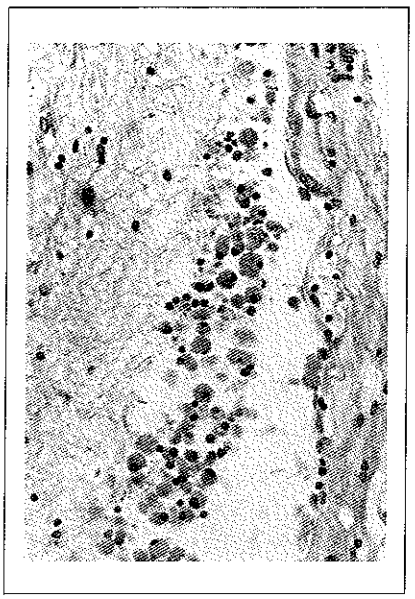


Fig. 4b. Glial scar in the region of the hemorrhage (*b*); a-X100, b-X400

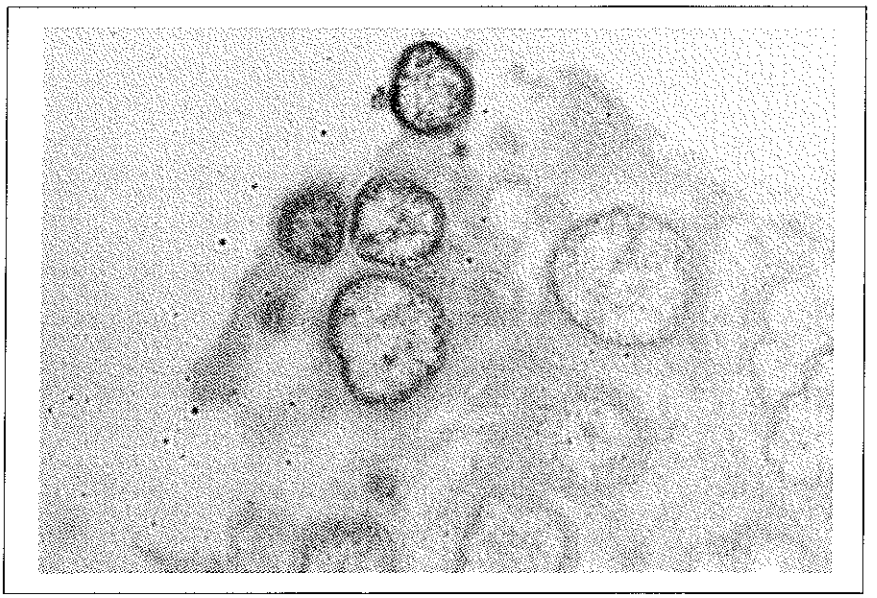


Fig. 5a. Expression of fos in cells: *a*-product of fos gene is localized in cell nuclei, semithin section, X400.

early stages of the tumor progression.

Recently it was found that the expression of these genes is a marker of neuron activation by various stimuli. The activation by active forms of oxygen is among them, too.

Two peaks of the expression of fos and jun genes are registered in at brain ischemia, which is caused in animals by arterial occlusion. The first peak of expression is discovered during the first hours after occlusion in the ischemic cells of the hypocampus and neurons of the II-Y layers of the ipsilateral cortex. That expression was continued till the time of the cells' death.

The second peak of the expression of fos is registered about the 14th day after the occlusion in the safe neurons and proliferative glial cells that form walls of cysts and glial scars at places of necrosis

It can be supposed that early and late activation of immediate-early genes has a different significance for cells at cerebral ictus. The early activation of these genes is provoked by ischemia and may be connected with the production of active forms of oxygen and lipid peroxidation. It is very likely that a high level of gene expression supplies tolerance to neural cells to ischemia, as described in experiments with hyperglycemia and growth factors. The late activation of immediate-early genes may be connected with processes of proliferation of glial cells and fibroblasts, which form glial scars or walls of the cysts after cerebral ictus. This activation correlates with production of some growth factors of neural tissue and is the main mechanism of regeneration. Expression of these genes is also detected adjacent to the region of ischemia-safe neurons, that cannot proliferate, but are subjected to hypertrophy and partly compensate for functions of dead neurons

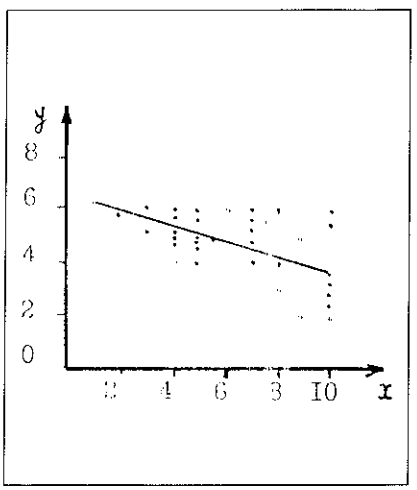


Fig. 5b. Expression of fos in cells: *b*-expression of fos (y) in lung cancer at different stages of tumor progression (x)
$y = 6,66 (\pm 0,52) - 0,28 (\pm 0,08)x$
$k = -0,55$; $P < 0,05$

5. Conclusion

The established phenomena of free radical lipid peroxidation and activation of immediate-early genes during different phases of cerebral ictus, mainly at the early stages, are of great significance in the development of the alteration of cells and compensation of their functions by safe neurons. These mechanisms can be very useful in creation of new methods of therapy of cerebral ictus, based on using antioxidants and activators of immediate-early genes.

Professor EUGENIA KOGAN
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DICK THORNBURG

The Disabled and the Law Throughout the World

What is the role of law in the field of disability?

How can the law help persons with disabilities achieve a more fulfilling and useful life?

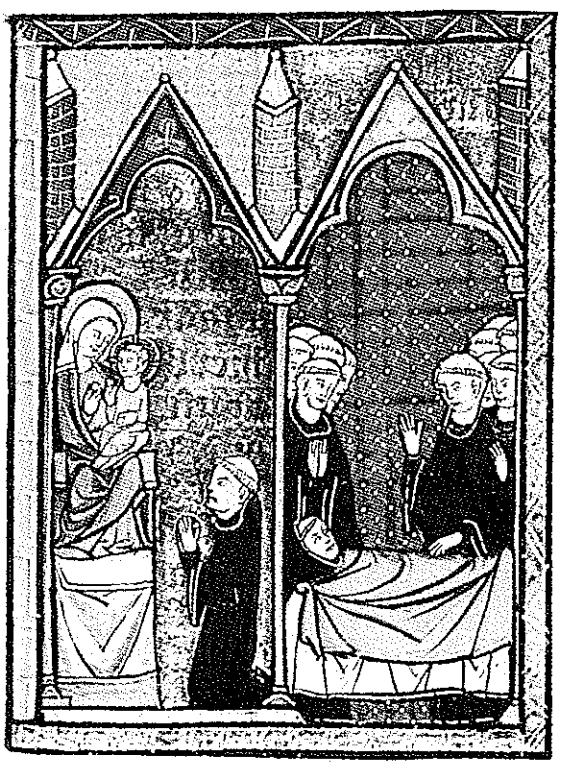
To answer these questions, it is first necessary to recognize that law only provides the framework within which justice and equality are pursued, rights are acknowledged, and human dignity affirmed. That framework is manifested in constitutional provisions, legislative enactments, regulatory and enforcement mechanisms, and court decisions. It must be firmly grounded in a commitment to the rule of law which undergirds the essential traditions of freedom and democracy.

To persons with disabilities, the law is not only a reflection of society's attitudes towards one of its most vulnerable groups; it is an effective vehicle for producing necessary changes in the allocation of resources and in shaping human behavior. Where law is established, it commands compliance. At its best, the law recognizes persons with disabilities as potential contributors to the socioeconomic fabric of a nation rather than merely passive recipients of special services and financial benefits.

It is clear that a worldwide shift in attitudes toward persons with disabilities must be intimately connected to the rule of law and effective legal institutions. But, as I have note, the law merely provides the framework for the pursult of laudable goals. While the law is a living, continuous process, mirroring and sometimes stimulating changes in society, it alone cannot create equality of opportunity and an end to discrimination. For this there is required the public and political will to guarantee that no person is denied, because of disability, those basic human rights and fundamental freedoms which we all cherish.

Let us then shift our examination from the general to the specific so that we may see how the law interacts with our overall aspirations for persons with disabilities

I speak mostly from my experience in the government of my home country, the United States of America, which provides a good example of how one nation seeks to deal with the challenges presented by disability. During my service as Governor of my home state of Pennsylvania during the 1980s, for example, we supported new initiatives for community-based (as distinguished from institutional) residential facilities for those able to take advantage of them, for an increased emphasis on " mainstreaming " special education stu-



dents, for improved work environments (including the concept of " supported work ") and for greater emphasis on independent living for those previously in a state of dependency.

All of this was pursued while, on the national level, significant laws were being enacted during the 1970s and 1980s to provide for the rights of persons with disabilities to obtain educational parity, access to housing, and the full use of public facilities.

It was next my privilege to serve as Attorney General of the United States and to work on the most comprehensive civil rights legislation ever enacted for persons with disabilities, the Americans with Disabilities Act. This act, signed into law on July 26, 1990, aims to benefit some 43 million Americans with disabilities by empowering them to enter the mainstream of society as contributing citizens free of

— Discrimination in the work place;

— Barriers to the enjoyment and utilization of public accommodations;

— Immobility in transportation; and

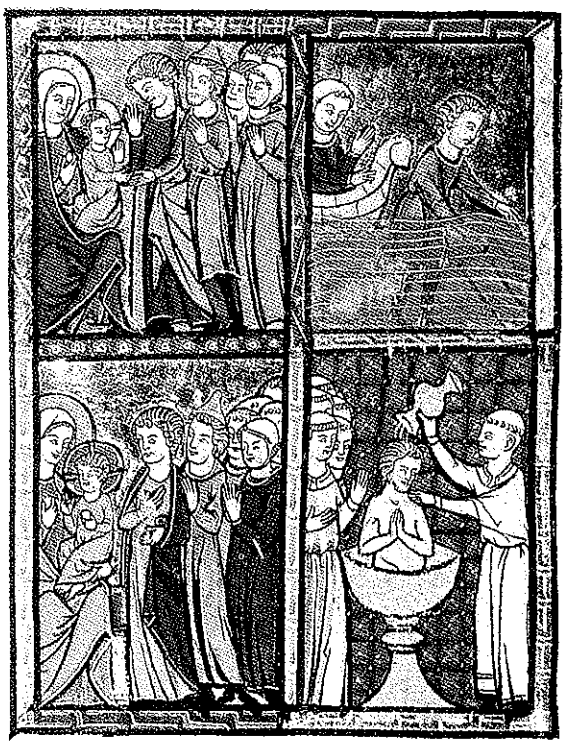
— Inaccessibility to telecommunications.

While the Americans with Disabilities Act is designed specifically for America, it includes elements which can be used in almost every country. For example, it provides for:

— An incremental approach with a time lag to take effect, giving the community ample time to prepare for compliance;

— Terms such as " undue hardship " and " reasonable accommodation " in defining compliance so as to avoid too rigid—and counterproductive—an application of the law's dictates;

— The opportunity for either governments or individuals to bring legal actions to force compliance.



Few of us among the 3,000 advocates and supporters of this important law who were present will ever forget the ceremony on the White House lawn, when President Bush signed the act into law, heralding a new day for those so long ignored in their quest for full citizenship.

During this same time period, many other countries have undertaken similar efforts to provide for increased legal rights for persons with disabilities. These initiatives have taken the form of either constitutional emendments or appropriate legislation.

Increasingly, it has been recognized that specific legislation should only be used when general laws cannot cope with the problems of persons with disabilities: they are best served when rights are granted and exercised in the same manner as those of other citizens. Gradually, it is also becoming more and more apparent that denying persons with disabilities full participation in society can impose tangible and intangible costs far exceeding those of providing direct access to community resources.

Let us look at some examples of recent constitutional and legislative initiatives in this area.

Among those are Brazil, whose 1988 constitution deals with special education, job training, and discrimination in terms of wages and recruitment, the elimination of architectural barriers, and a percentage-hiring quota in the civil service for persons with disability.

In December 1990, China adopted its Law on Protection of Disabled Persons, prohibiting discrimination, insult, and injury against the handicapped or their ill-treatment and abandonment, in implementation of the constitutional guarantee that persons with disabilities must enjoy the same civic rights as the able-bodied.

The Philippines enacted its Magna Carta of Disabled Persons in March 1992, providing substantial penalties against discrimination and supplementing constitutional provisions designed to protect disabled

persons and providing for the appointment of a member of Congress to represent their interests and their organizations.

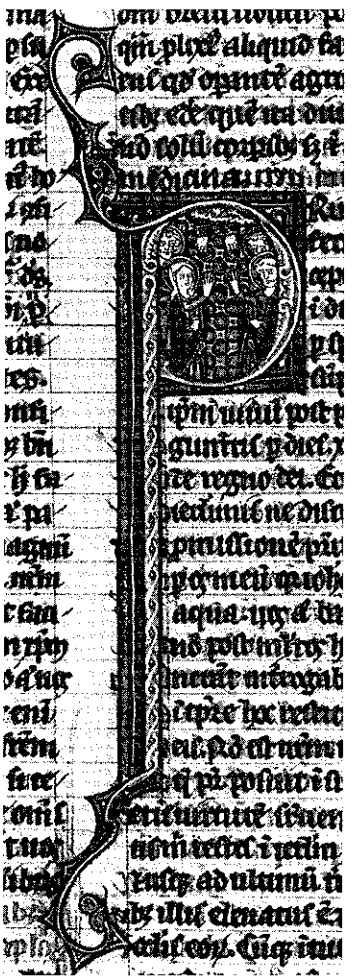
In Sweden the Support and Services Act for Persons with Certain Functional Impairments will enter into force on 1 January 1993, as a result of a special parliamentary inquiry into the concerns of persons with disabilities. It will provide better access to employment, transport, and housing and underline respect for self-determination and user-participation, while outlawing coercive measures against persons with intellectual impairment.

Zimbabwe recently promulgated the Disabled Persons Act of 1992, which ensures equality of opportunity for earning a living, enjoying appropriate housing and meaningful jobs and leisure activities. It calls for the establishment of a National Disability Board, the majority of whose members will come from persons with disabilities and their organizations.

In addition, an increasing number of nations have created cabinet-level positions to advocate for disability rights. Many are also appointing persons with disabilities to prominent positions in government where they can serve not only as effective advocates, but as role models of accomplishment and distinction.

All of this recent activity takes place against a backdrop of increased international recognition of the importance of disability issues through the United Nations. Since 1982, the United Nations, through its International Year of the Disabled, the Decade of the Disabled (1983-1992), and now the establishment of each December 3 as an International Day of Disabled Persons, has sought to focus public attention on the problems of persons with disabilities worldwide.

While these observances have played an important role in raising awareness and shifting attention away from a charity approach toward an integrated social development approach focusing on capability, the UN response, it is recognized, must be more than rhetorical.



Perhaps the most ambitious, substantive UN undertaking was the adoption by the General Assembly nearly a decade ago of the World Program of Action Concerning Disabled Persons, setting forth specific goals to be reached during the Decade of the Disabled and recognizing the need for governments " to create, through legislation, the necessary legal bases and authority for measures to accomplish the objectives " of the Program.

A close observer of both the United Nations and the disability field has summarized these objectives as follows:

1) to increase participation of disabled persons in social, cultural, religious, recreational, and community life and in decision-making at all levels;

2) to expand education, training, and job opportunities;

3) to remove all barriers—architectural, transportion, communications, and legal—to full participation and equalization of opportunity;

4) to increase acceptance of disabled persons through communication and education programs;

5) to prevent disabling diseases and conditions through expanded immunization and improved environmental, occupational, and other health programs;

6) to prevent disabling accidents at home, at work, on the road, everywhere;

7) to restore sight, hearing, movement, and communication to disabled persons through increased access to known, appropriate measures and developing technology;

8) to expand community-based rehabilitation services and self-help programs involving disabled persons and their family members;

9) to conquer or cure major disabling conditions through greater and more purposeful application of biomedical research;

10) to involve everyone—disabled and non-disabled, young and old, rich and poor, men and women, from every country, culture and creed—in cooperative efforts at local, national, regional, and international levels to conquer or prevent disability and release human potential for the benefit of all.

This adds up to nothing less than developing and utilizing the full potential of all those half billion persons with physical, sensory, and mental disabilities who look to us for leadership.

Just last month that leadership gathered in New York at a Special Plenary Session of the United Nations General Assembly to mark the end of the Decade of Disabled Persons. That Session heard from Secretary-General Boutros-Ghali and many world leaders, including those from nongovernmental organizations, gathered for the purpose of beginning to set an agenda for the post-Decade era.

Perhaps of equal significance was the first-ever gathering of Ministers from some 73 nations who hold responsibilities in the field of disability, in Montreal, Canada, just prior to the special session. Their two-day dialogue similarly focused the attention of those persons in the front lines of efforts to deal with disabilities in their home countries on the agenda for the future.

Out of these deliberations, it is hoped and expected, will come a new and heightened series of commitments by the UN and Member States to facing the challenges of disability worldwide.

On the operational level, the focal point for UN action is the Center for Social Develpment and Humanitarian Affairs in Vienna. During the Montreal session, I suggested that the CSDHA should henceforth concentrate its attention on three separate areas:

First, to act as a clearing house for programs and ideas that can be shared and replicated worldwide.

Second, to continue the role of standard-setting, including the establishment of a strong legal base through projects such as the Draft Standard Rules on the Equalization of Opportunities for Disabled Persons, just completed in Vienna by a special Working Group of the Commission for Social Development.

Third, to effectively aid in coordinating the activities of United Nations agencies such as WHO, UNICEF, ILO, UNDP, and others active in the disability field.

In addition, a new effort should be made to translate the commitments of the Decade of Disabled Persons into action and to carry forward the World Program of Action on a regional and country basis within the UN framework. Holding great promise in this regard are the five United Nations Regional Commissions, one of which, the Economic and Social Commission for Asia and the Pacific, has already designated the years 1993-2002 as its own regional Decade for Disabled Persons.

The UN also has responsibilities, exercised through the Commission on Human Rights, to ensure the absolute observance of the human rights of persons with disabilities worldwide. This is, no doubt, an area which will command increased attention in the years ahead.

Before closing let me say a word, in particular, about the developing nations of the world, wherein, it is estimated, some 80% of the world's disabled population lives. Most of these persons are at the margin of their respective societies.

Priority concerns of just surviving—combating hunger, securing shelter, and eking out a daily existence—unfortunately take precedence over concerns for people with disabilities.

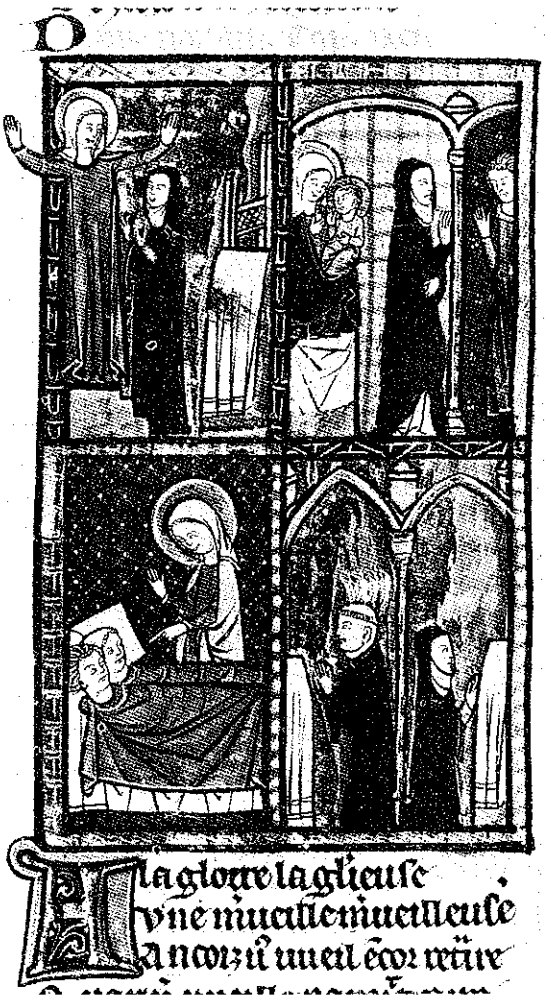
It is sometimes said that, in nations struggling with a full agenda of political and economic problems and the effort to achieve basic human rights for all their citizens, the interests of persons with disabilities are likely to be set to one side for " future consideration, " i.e., when these other more

important matters have been addressed.

On the contrary, I would suggest that what responsible leaders of developing nations need to realize is the unique opportunity they have to embed disability rights in their emerging institutions as part of their development efforts, to build an infrastructure of government, economy, and human rights that includes and respects the interests of persons with disabilities from the very beginning. For it is no exaggeration to say that the way a society treats its citizens with disabilities is a valid measure of the quality of life and respect for human dignity in that society.

This is the essential challenge we all must face in the years ahead. In the meantime, we are all indebted to the Pontifical Council for Pastoral Assistance to Health Care Workers for helping us to focus the world's attention upon this challenge and on the need for an effective response.

Hon. DICK THORNBURGH
United Nations Under-Secretary-General for Administration and Management, New York, USA



HAROLD WILKE

The Social and Psychological Barriers to Accessibility: Is the Ramp Enough?

The presence of each of you, as caregiver and expert in caregiving, underscores the importance of the response of the world's congregations and caregivers to pastoral care for all the children of God

I begin with a personal incident, from which I draw a series of " learnings, " or teachings, which I feel are basic to the caring response of individuals and congregations.

The Caribbean waters were sparkling in the sun, inviting me in for refreshment after my lecture in Bridgetown. After a half hour in the ocean and on the beach, I started back to the hotel, only to be accosted by a young man: " Mister, I saw you a half hour ago, coming down to the beach, and I noticed you had an arm off, so I was sorry for you. " I murmured non-committally, and he spoke further: " Then I saw you put down your beach blanket and take off your shorts and shirt (I had of course got into my swim trunks before I arrived at the beach) and I saw you had *both* arms off, so I was very sorry. " I murmured again, and he went on: " Then I saw you plunge into that first big wave, and soon you had swum way out in the bay, so I wasn't so sorry any more. "

His last words were: " You swam back and dried off. I watched you put on your clothes, and I wasn't sorry at all! "

Not sorrow, not pity, but the full panoply of acceptance and understanding, the assumptions of total involvement in the world and family life and recreation and all else that goes with being a full person in our society—that is the need and desire of the person with a disability. It is also the need of our society as well.

The first specific criterion for full inclusion in society for the person with a disability is justice: namely, that society respond justly —fairly and equitably—to this individual. Fortunately for us in the USA, a recent government action mandates precisely that justice, in the Americans With Disabilities Act, created under the magnificent leadership of the previous speaker, the Honorable Dick Thornburgh. I also participated by offering the invocation, thus fulfilling a significant part as *symbol* and as *participant*, even with a perceived disability, and as a provider of meaning /content for the event.

A sense of justice—that the community around one, the whole society in which one is set, is arrayed for—not against—the individual, includes the idea of availability of jobs and work, an accessible physical infrastructure, adequate transportation, and various levels of communication, and a general acceptance of the need for full inclusion.

The Blessing at the White House

That sense of justice is noted in my Blessing for the Americans With Disability Act, a religious statement presented at the White House signing, in which I merge the concepts of religion and justice. On the White House lawn that day were four thousand people, almost all with various disabilities, and many Senators and Representatives, the entire Cabinet, and the President and Vice President of the United States. In my Blessing for the ceremony, I said (and I quote now only the first few lines):

" Let my people go! " was your desire, O God, commanding that all your children be freed from the bonds of slavery. The parting of the Red Sea was your act, O God, ensuring that your people could have access to the Promised Land. From ancient times to today we celebrate the breaking of the chains holding your people in bondage; now in the Act of the Congress and of the President of the United States of America, in the passage and signing of the Americans with Disabilities Act, providing for forty million Americans with disabilities new access to the Promised Land of work, play and service: full citizenship in this nation, overcoming the barriers of architecture and communications. Bless our President as he signs the Act, and strengthen our resolve as we take up the task, knowing that our work has just begun.

" Let this Act also change attitudes: discarding old beliefs that sin is always the cause of disability, the old attitudes that cause too many people to look down upon persons with disabilities. So may all your children be fully a part of this society and of your Rule upon earth, that all may enter the new Promised Land of the Acceptable-/Accessible Year of the Lord! Amen.

Church Affirmation of Pastoral Care

The Church's concern for Pastoral Care is reflected in a whole

series of Encyclicals and statements, one of which I noted personally during Vatican II, when I sat in the Delegate Observers Box in the Basilica: On the last day His Holiness Pope Paul VI brought before all two thousand bishops present several persons who were part of the disability community, and assured them of the same blessing God gives to us all, recognizing their wholeness in a whole community.

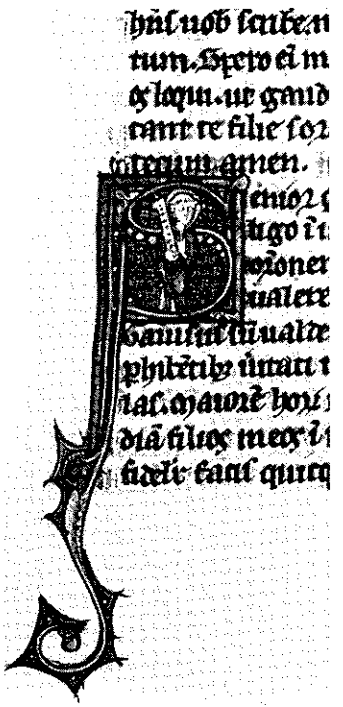
So, our learning is: " A group which does not have within it the input and learnings of persons with handicaps is itself handicapped. "

That young man on the Caribbean beach saw me, finally, as a whole person: Wholeness is a reflection of all a person is: the gifts and strengths present rather than that which is missing. The young man saw I could swim, and I could dress myself, so he could assume I was whole even though my arms were missing

For us in religion, God's assurance of our wholeness is based on the divine word of our being children of God, made whole in the redemptive work of Jesus Christ. He has broken down all the walls of separation: " Neither life nor death, .. can separate us from the love of God, " and we can be true to the Scripture as we add, " neither illness nor disability. " Or, again, as in the Epistle of James, " neither Jew nor Greek, slave nor free, .. we are one in Christ Jesus, " we can add " neither disabled nor 'abled.' " God makes us whole! And if we are whole in God's eyes, no earthly person can say otherwise!

Even in common language we recognize such inherent wholeness: A rose, we know, is still a rose even with a petal missing!

The outer package of a person is not nearly so important as the inner being. Persons with disabilities face constantly the false idea that the outer appearance defines the individual. Every Christian and every congregation to its peril sees only the outer husk; every Christian and every congregation to its peril sees wholly (and holy!) the person with a disability!



Using All Resources

" Using everything you've got! " is a concept we use to overcome difficulty or loss; we " make do "; we cope; we use the strengths and abilities left us to compensate for those taken away.

Our friend on the beach did not put this concept into words, but he saw it enacted before his eyes; one *can* swim and dive without arms; one *can* dress without hands.

And, of course, one can use a wristwatch without wrists. Mine becomes, for example, an ankle watch, which—when people notice—always gets a reaction. It happened on a trip last month. The flight attendant saw me reading a book, holding it with my foot, naturally, but her eyes fastened on the watch on my ankle, and she blurted out, " You're wearing your watch on your ankle! " I responded, with a sly smile, " It's the latest style! " She smiled back and went on her way, but I was left to meditate again on the many alternatives open to us all and how with imagination we can fulfill them.

A better phrase for this concept is " Using Your Third Eye "—that inner vision—that imagination —which offers alternative, additional, or novel approaches to particular tasks. Thus, even the ramp into the house of worship can take many forms and fit into many places.

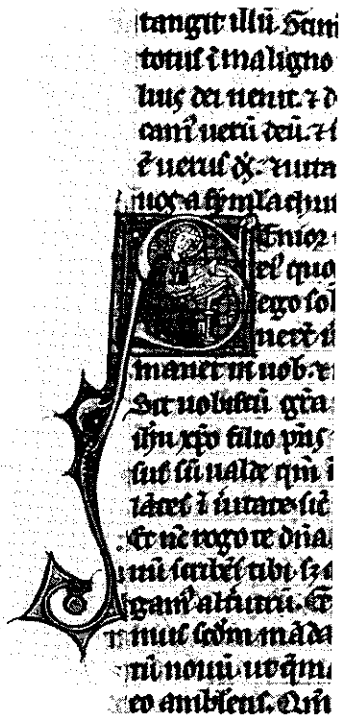
Jesus told of the paralytic (a man with a spinal cord injury, we might say now) whose friends broke a hole in the roof to allow him to enter. We need not go that far today, but there are always many more ways to enter than we assume. Let our imagination take hold! Let our third eye find alternatives! Let us be as imaginative as the man in Jesus' story! The inner resources of the human psyche and the human body are limitless. That man on the beach could dimly sense some of that. We tend to see these resources as outer ones (and that is good, too). So I mention your congregation's newest resource, the book *That All May Worship*, edited and produced by Mrs. Virginia (" Ginny ") Thornburgh (a speaker at this conference)—and two books of mine, *Creating the Caring Con-*

gregation and *Sharing With Caregivers*, plus the wonderful pamphlets and audio-visual brought into being by Msgr. Cribbin and Mary Jane Owen (also speakers here) through a special committee within the Catholic Church, in America.

Ultimately, our resources are those God-given strengths of the spirit: Jesus said, " You can do anything. "

You would of course expect that a Protestant clergyman would naturally speak of a particular resource in the church that has been of inestimable value: the pastoral ability of women ordained to the ministry. My own denomination, United Church of Christ—a union of two historic groups, Congregational Christian and Evangelical and Reformed—has ordained women for over a hundred years. Just one instance of their gift to the Church: when fewer candidates for ministry showed some two or three decades ago, the women were there to help keep all our pulpits open. And for me personally, as an adjunct professor at New York's Union Theological Seminary, I constantly recognize the academic and personal abilities of my women students.

Dear friends in the Catholic Church, Your Holiness and Your Eminences, the concept of " using everything you've got! " reminds *you* of what you have known for two millennia, the graces and abilities of women in the church. For me as a Protestant, I grieve to note that we have not used this gift fully—by ordaining women—until the last hundred years, and I joyously note the ways God has strengthened the church, in pastoral care and preaching and administration and teaching, through the fullest acceptance of women in the life of the church.



The Call for Mercy

The young man's " I was sorry for you " offers another learning for us, that of the related concept of " mercy. " Our Bible—indeed the Holy Books of all the world's religions—stresses divine mercy and in response sets forth mercy as a human attribute of highest importance. Emphasizing the divine level, a church group has modeled its work on the the teaching of Sister Justina of Poland (recently beatified, through the gracious act of Your Holiness), in whose life and work the divine mercy was central. The American convent in Florida, under Servant Mary Paul, was my host last year, as they considered mental illness and prayed and hoped for a more humane response to the sufferings of persons so afflicted. My lectures were of course dependent in part on the years I spent as a chaplain in mental hospitals, and the years I was on the faculty of the Menninger School of Psychiatry. But far beyond psychiatric concepts, important as they are, is the sure knowledge of God's mercy and forgiveness. A piece of history—part of it bizarre—is relevant here:

" My advice is to throw this retarded child into the river. " These harsh words from the lips of an eminent sixteenth-century theologian, spoken to parents of a child born with multiple handicaps, reflect an attitude prevalent in many parts of the church throughout its history. This attitude still exists today.

Persons with handicaps were invariably " cast-offs " in medieval Christendom and in most secular societies. When various illnesses or disabilities hindered persons from getting along in their communities or when they couldn't be properly diagnosed or simply when their families found them difficult to live with—such persons were, so to speak, " thrown into the river. " Frequently, they lived out their pained lives wandering aimlessly on roads and byways, the butt of society's inability or refusal to accept them.

Community Care

While the church has often rejected persons with handicaps and illnesses, it also has a rich history of responding to human need. At times the church has offered and developed institutional care as a necessary antithesis to thoughtless or even abominable neglect in soci-

ety. For instance, an important Gospel-inspired institution, Bethel-bei-Bielefeld (" City of Mercy "), was created in Germany for homeless, mentally ill persons. They were given genuine, caring, loving, witnessing support. But the church has also expessed its concern for a noninstitutional approach to human health, some of it inspired by St. Dymphna in Gheal, to whom people from across Europe began flocking, to be cured of mental illness. When Dymphna was canonized, she was claimed as the patron saint of the mentally ill, or, by extension, of all persons ill in body, mind, state, or spirit. Mentally ill pilgrims continued to come to Gheel. But, remarkably, no institution was ever built. The pilgrims were cared for in the homes of local church people. To this day, a tradition of parish- and home-centered, extrainsitutional care is practiced in Gheel. The town is an " institution " which is *not* an institution.

A mixed response, both institutional and beyond—to primary community care, was adopted by Kaiserwerth, a small town on the Rhine almost totally destroyed by the Napoleonic wars in the nineteenth century. There, a young pastor named Fliedner began a ministry of faith-centered home and community care for the ill and diseased. he statred a nursing order, which, with the later assistance of Florence Nightingale, was the beginning of professional nursing care (The stress on professionalism for women was an early contribution to women's liberation). Pastor Fliedner's nurses, who were dressed in the respected German hausfrau uniform, were eventually acepted as leaders throughout all of Europe.

A local congregation today can reach out to both options, in caring for the disabled: insititutional and community, both God-centered. Today we continue living in the tension between community care, symbolized by Pastor Fliedner, and insitutional care, symbolized by Bethel-bei-Bielefeld.

These histories help us understand health, healing, and wholeness more clearly as we seek to minister to persons who are ill, aged, and handicapped. Wholeness

involves seeking out the alienated of our society often rejected by the church: those just out of prison, returned from mental hospitals, physically disabled, or retarded. Wholeness necessitates our concern for lifestyle; home, church, and community support; and loving relationships.

Health and healing must be discussed simultaneously with salvation, each bearing on the other. Healing is more than a medical relationship with a physician, more than the latest scientific equipment in a hospital. It begins with a justice relationship in a community which provides sanitation, adequate nutrition and drinking water, and human dignity.

As a church—a local congregation—we work for health, healing, and wholeness. Architecturally, we make it possible for individuals in wheelchairs to get into church. In our preaching, sharing, and fellowship—in our entire attitude—we need to affirm, " This person is a child of God, along with me, and has gifts for us as well as needs from us. This congregation is part of the church, the Body of Christ, and must therefore express the whole of God's realm. " That young man in Barbados also must have seen in my bearing, my outlook, my " I'm OK " aura, my self-possession, an element of personality which can be a part of every person: the sense of personal importance and of self-worth, a sense of being *central* to life. Sigmund Freud called it the " Oceanic feeling, " the sense that we are supported psychologically even as the salty ocean supports us physically. Freud pointed out that beginning in the womb we float, totally supported, with all our needs met. After birth we continue in a sea of support: hungry, we are fed; tired, we sleep; in pain, held in the arms of mother or father. Our needs are met before we ask! Our parents, and later our siblings, too, provide such an ocean of support. Parenthetically, think how this understanding highlights the importance of family life education, of the basic values in the home. The local congregation must constantly uphold and strengthen family life and living. Parental support, including

challenge—was critical in my own life. Their support—their acceptance of me, had to climb mountains of rejection by others. Some early incidents set it in context:

" I heard the church bells this morning toll the death of an infant, and I was hoping it was your poor little crippled baby. "

I was three weeks old when these words were spoken to my mother by a well-meaning acquaintance from church at a chance meeting at the grocery store. I was the " poor little crippled baby " born with no arms. My birth caused a stir in our small community, a torrent of tormenting, accusing questions for my parents, and a string of experiences: rejection and acceptance, pain and healing.

My mother had ample occasion to rely upon her strong Christian faith. The encounter with the woman in the grocery store was indicative of a greater struggle she —and eventually I—would have to face. There were bitter hours when she felt utterly alone with what she had brought forth.

My mother, constantly confronted by a pool of panic, experienced rejection even from our local church. In a few years, the public school was firm in their refusal to accept me as a student.

Rejection is an all-too-common experience for persons with handicaps and their families—and, in some cases, *from* their families. Our society, which so prizes normality, conformity, and physical perfection, has fostered a tragic history of rejection. Even so has the church.

Home and Community

Many neighbors and friends within our church and community, once they dealt with the trauma of their own brush with vulnerability, came forward and rallied to our support. Shy at first, like that curious, limited woman in the grocery store, they soon offered me and my family what they had: the stability of a caring congregation, a caring fellowship. Through their acceptance, I was enabled to get involved in all the normal range of church and community.

Surely the most significant factor in my growth was my home life, rooted in the solid faith of my parents. One of their gifts was inculcating in me a sense of self-reliance and personal responsibility. Such " self-starting " certainly wasn't guaranteed at home—any parents' tendeney to " smother love, " bred in guilt feelings, may radically inhibit growth. Nor is self-dependence impossible in an institution. But I was lucky. My parents had a high level of expectation for me, and they worked with me to help me achieve it.

It started very early: once, when I was two or three years old, sitting on the floor of my bedroom trying to get a shirt on over my head and around my shoulders, I was having an extraordinarily difficult time. While I grunted and sweated my mother stood watching. Her arms must have been held rigidly at her side; every instinct in her wanted to reach out and put my shirt on for me.

Finally, a neighbor who was visiting asked in exasperation, " Why don't you help that child?! " My mother responded through gritted teeth, " I *am* helping! "

Her painful withholding of help *was* helping me. And my pain and sweat level, while high in that moment, was being reduced in the long run as I learned the crucial lesson of responsibility and self-motivation. That was for me an important component in my own health and wholeness. So were my father's painstakingly patient efforts at allowing me to help myself—to learn to swim, or play, or fulfill farm chores. Countless other caring gifts they gave me—and helped me to give to myself. So, to all parents we can say that coping with the problem and working out circumlocutions or special patterns makes it possible for the child to be the one who finally has to do it. The parents' forbearance has helped the child toward independence.

Not only the child or the parent, but all in society: older, younger, disabled or " normal, " all of us in it together, learning from each other, exulting in each other's successes, supporting each other in our

difficulties, and celebrating in growth and creation!

Including the " Patient " In Caregiving

Priests and other caregivers within the congregation do know that the vulverable, the alienated, the " difficult ones " are at the heart of the congregation's concern, more central even than budget or program. Further, we see them as part of the solution, not primarily as a problem. They are not so much *objects* of mission as they are *participants* in the mission. In medical terms they are part of the therapeutic team. So we in the congregation adopt both concept and terms: we become a *healing team* The church becomes a healing community. We care, pray, and work for each other. Our love for all God's children includes the stranger and the outsider, the one Jesus called the lost sheep, more important than the ninety-nine within the fold.

So your congregation becomes not a fortress to protect those inside, but a plaza, a mall, an open place, accessible to all. It is the house where Jesus spoke, (*Mark* II) accessible to the paralytic, and by extension, open to all alienated and lonely and dispossessed persons.

Within this healing community, caregivers include " the patient, " the one in special need of healing, and also include " the expert, " the professional, all who can offer their gifts in this therapeutic team. Nor do we forget the architects, the builders, who with imagination and expertise make the House of God accessible to all.

A Toxic Environment and Disability

Birth trauma and early childhood illnesses with consequences which develop later are a major factor in disability, estimated at one-sixth—16%—of that population. An astonishingly large number of them are preventable, through proper prenatal care and a healthful environment. The consequences of poor diet and the abuse of drugs—alcohol, tobacco, and the like—on the part of the pregnant woman are tragic, as well as a denial of God's word that our bodies are temples of the Holy Spirit. Nor is the pregnant woman alone responsible: Living in an environment of smoking, or of easy access to drugs, make the father also involved. Additionally, the HIV " AIDS " babies wring our hearts.

A toxic environment has many elements: It includes industrial pollutin, impure water, permissive attitudes to drug use, the lack of stringent governmental standards for drug testing of people at risk, indeed a general social attitude which almost ensures accidents, on highways or in homes, death and disability by handguns not properly regulated, industrial accidents where safety precautions are not required—all these and many others mean that we live in a dangerous jungle.

War and Warring

War's death, destruction, wounding, and societal disruption—millions of starving refugees whose later life-long illnesses and disabilities will be a major economic and physical and psychic cost for generations is of critical importance. Two brief illustrations: the average height of a young French man was one inch shorter than his previous generation's counterpart, a result of te Napoleonic Wars. More recently, the death and injury toll of today's children in Guatemala, Iraq, and Libya is tragically much higher than normal because of land mines sown in war but reaped years and even decades later: Dragon's teeth indeed!

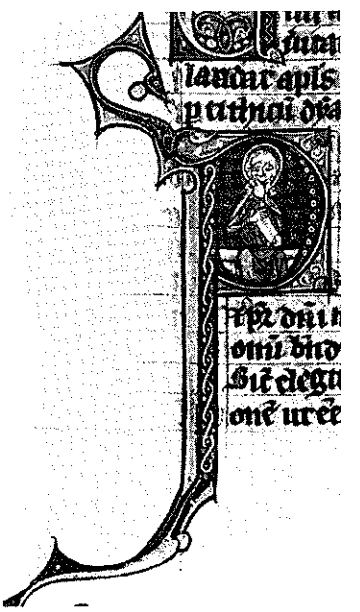
A Christian who values life, who wishes to be known as " pro-life, " has an awesome litany of life to fulfill: to be " pro-life " means to be a proponent for peace, to be an advocate for handgun control, to push for legislation for a clean environment, to oppose the death penalty, to seek justice and healing for abused children, to end violence toward women.

Deeply personally, " pro-life " has a poignant meaning for me: had my mother known my abnormality in the womb, and had she decided I should not be born, I would not exist. *Not to be is an awesome thought to contemplate!*

" Lord, where can we turn? Thou hast the words of eternal life. " So we seek in Holy Scripture the words of solace and comfort, and indeed of challenge as well

a) " The Eternal God is Thy Refuge, and Underneath are the Everlasting Arms " (*Deut* 33, v. 27) is a verse I latched onto from childhood. Obvious, perhaps, since I had no arms of my own (a genetic accident) that I would then look to God for my lack. Indeed, Scripture here says that for all humankind. It is not in our strength ... our " own strong right arm ". but in God that refuge and support are provided.

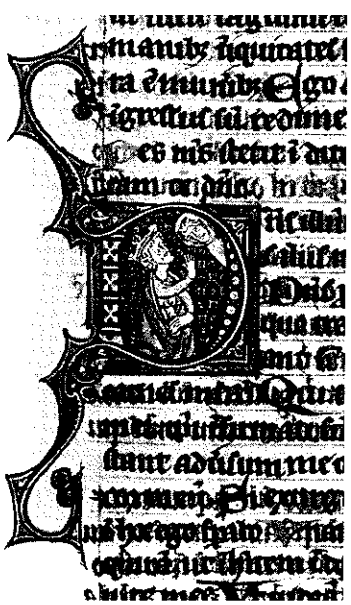
b) *Ta de Me Blepomena Aionia* (*The unseen things are eternal*) was carved in stone over a doorway in a theological seminary where I once studied. The phrase kept reminding me that the daily stuff of life is not as important as those unseen things ..love, understanding, appreciation, hope, joy, peace, which are part of the eternal warp and woof



of our common life leading to the eternal And the cadence and rhythm in the Greek continued to haunt me.

c) We must do the work of God while it is day (*John* IX, 5). These words of Jesus were spoken directly to His own disciples and to a man born blind, who is about to be made to see by washing in the Pool of Siloam at Jesus' command, but who at this point is still blind. The phrase conveys Jesus' own assurance that the ministry belongs to every person regardless of that individual's varied failings or difficulties or disabilities. Each of us is a missionary, each a worker in God's realm. This is a sharp contradiction therefore to the statement in Leviticus, prohibiting persons with disabilities from participating in the proclamation and dispensation of God's Word.

d) " The Lord is my shepherd; I shall not want " (*Psalm* 23, Verse 1). These beloved words from the Psalm were of instant recognition for me, repeated aloud in the " back forty " of our farm as I brought in the cows for milking and feeding. But even today, in an industrial society, " shepherd, " translates easily into " caretaker, " and we see that God provides all our most basic needs.



There was no congregation on that beach in Barbados, but we two people were gathered, perhaps not in God's name, but certainly under the divine care. So, now, as Catholic congregations around the world, what learnings—teachings—watchwords, do we take to our congregations?

Surely, our growth together as God's people has taken us beyond ramps, elevators, and special programs for " those " handicapped people to the realization that God's people includes all of us. We now recognize the limits and gifts of all people. We think of persons with disabilities as persons with untapped assets that are needed for the whole of God's people. We can also take the lead in dealing with the emotional and spiritual barriers that too often hinder true participation and belonging.

Principles of Healing

A major task is biblical and theological study for this ministry. God speaks to us in the Holy Word of Scripture, so we need to study the Word anew in the light of this problem (no, not " problem, " but " opportunity! ") As we read scripture, and reflect theologically, we arrive at some basic understandings about " inclusiveness " and " accessibility " and " healing " and " wholeness. " Some of these understandings can be set forth in several principles:

Healing is a function of every congregation.

Healing exists in every caring, sharing, accepting intentional mobilization of these forces within the religious group, which has by its very nature an interest in these transcending interpersonal values: to facilitate the making whole of broken, disabled, alienated persons

Instant miraculous cures, healings from one charismatic person do happen, with God's grace, but our congregation's primary concern is to draw out the healing inherent in every religious group—as a community of faith in God and of mutual support of its members. One of our congregation's missions is to fulfill its own task of religious health, of salvation, of healing support by members one to another.

We are advocates seeking to see more clearly and fulfill more adequately our ministry with persons with various kinds of handicapping conditions. Healing takes place as these individuals are received into the community of the faithful, each member providing support for the other, and receiving support from the other. The congregation is the healing community.

So we proclaim:

" God heals, a healing which can remove disease, deformity, disability, and their effects. "

" God's healing can come through prayer, faith, medicine, concern, appliances, therapy. "

" That healing can take the shape of patient endurance, companionship in pain, honest realism, quiet encouragement, healthy compensation, diversion, and humor. "

" God's healing can correct injustice in society, provide opportunities often denied, release people from confinement, equip and inspire reform. "

" This divine healing brings victory over human limitations, for the persons with disability and for the society that regards the disability as more prominent that the persons. "

" God's healing enables the person, in his or her own understanding and in the appreciation of the community, to become a whole being. "

Only a few weeks ago, at the United Nations in New York we held a Thanksgiving Celebration for the fulfillment of the U.N. Decade of Disability. For that service I created an Affirmation, applicable to us in the church as well as to the United Nations:

That All May Worship!

We affirm the right of all people to worship and serve within their particular Household of Faith, and the *responsibility* of all congregations to open the House of Faith to all, excluding no one because of age, gender, or disability.

We therefore advocate for an accessible society in which the religious community and persons of faith, regardless of their disability or situation, may fully express their whole beings and live out their spiritual selfhood

The world's half billion people with physical, sensory, or mental disabilities, and the additional half billion family members of such persons, have an inherent value to society and a right to use their gifts within that society and their Household of Faith.

We end now, not on a beach in the Caribbean, but in the hearts and minds of God's children everywhere and in Houses of worship, worldwide. We pray, in closing, a prayer offered only a few months ago, also at the United Nations:

O God, Creator,
maker of humankind in your own image,
who create the earth, our Eden,
our dwelling place, pure and undefiled,
who place divinity within each of your children,
God, Creator, help us keep our bodies and minds
temples of your spirit and images of your
divine being.

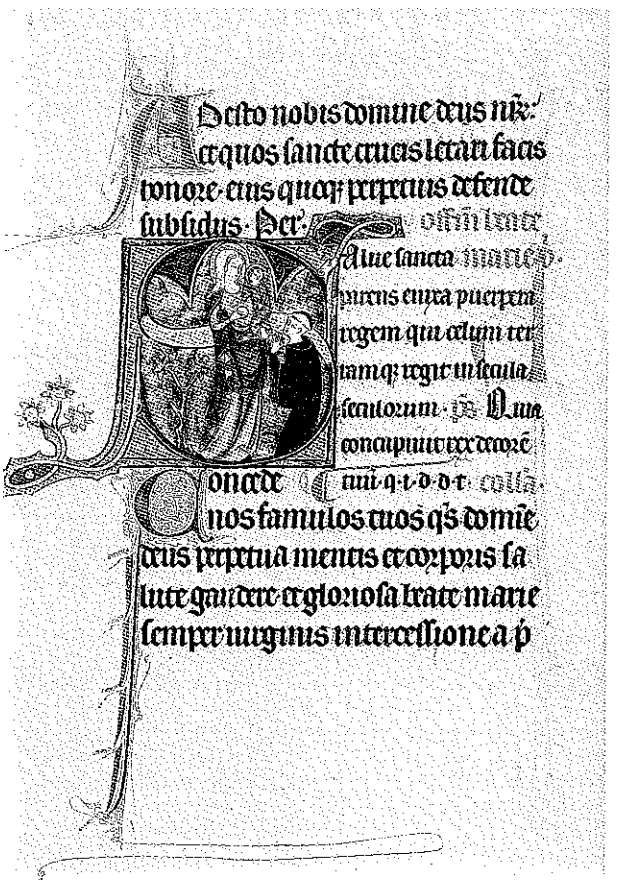
* * *

O God, Liberator,
you whose concern begins with liberation,
who command oppressors: " Let my people go! "
Who desire the loosing of shackles of slavery,
destroying chains which hold down people with disabilities,
God, Liberator, free your people!

* * *

O God, One God, whole, wholly holy:
who see us as whole,
even when those about us would make us less,
who remind us that a rose is still a rose
even with a petal missing,
God, whole, help us to claim
the wholeness you grant.
Amen.

Rev HAROLD WILKE
Member of the World Commission for the Decade of Disabled Persons, Washington, USA



MARIE HÉLÈNE MATHIEU

The Mentally Handicapped as Protagonists in Society

Those of you present at the end of this very full day are very courageous. But I think that you must also be very tired. During these few moments that we will pass together I would like, simply, to consider one experience—that of Faith and Light, to which both Cardinal Gagnon and Monsignor Tettamanzi have already referred in very friendly terms during the course of this conference.

This experience demonstrates in a way that is better than words that the handicapped person can be a protagonist of unity, a " builder of the community. " But this does not come about automatically. In order to fulfill this vocation certain conditions are necessary. In particular, it is necessary to overcome our instinctive reaction, which often takes the form of fear, escape, or even rejection, and to establish around the handicapped or disabled person a community of peace and of tenderness.

The Faith and Light movement was born from an unknowing rejection, from a crisis of suffering, and from a response of hope.

Camilla and Gerardo came up against unknowing rejection in 1968. Together with their two highly handicapped children, they wanted to enroll themselves in the diocesan pilgrimage to Lourdes. The reply that they received from the secretary was " impossible. " Their children were too handicapped and would have disturbed the journey without being able to take advantage from it. Camilla and Gerardo then proceeded to go to Lourdes independently, without being involved in any organization. But what suffering they had to undergo in the hotel where they did not feel welcome but had to eat their meals in their room so as " not to disturb the other guests "! Or in the sanctuaries where the looks they received and the words uttered declared: " when you have children like that it is better to stay at home "!

After a while, this married couple gave private expression to the desperation that they felt during that pilgrimage. We were there when they did so. Both Jean Vanier and I are parents. In 1964 Jean Vanier created the first Ark community in a village in the North of France. It consisted of small centers where the mentally handicapped and those who look after them take part in the same family life. As far as I am concerned, at the Christian Office for Handicapped People I very often meet parents who feel this trial, and the loneliness which follows from it, very greatly. The idea was born of organizing a pilgrimage only for the handicapped, their parents and friends, and especially for the young. Communities composed of twenty to thirty people were to prepare the pilgrimage together and would thus learn to know and love each other. It was not going to be a pilgrimage for handicapped people but by them. The whole of the liturgy and the program was going to be ori-

ented towards their capacities and abilities.

The preparation lasted three years. At Easter, in 1971, there were twelve thousand of us, pilgrims from eighteen countries. Five thousand were mentally handicapped. I remember that there was a man who had been discharged from a psychiatric hospital. He had gone in fifty years earlier. At Lourdes we experienced days of grace, peace, and friendship of a kind that we never expected to encounter. On the last day the pilgrims could not face up to going back to loneliness and desperation, to being scattered in the cities and towns where they lived. A cry went up: " this must go on. " Thus it was, that at the foot of the grotto, the movement of Faith and Light was born—the work and inspiration, we believe, of the Virgin Mary herself.

The communities created because of that pilgrimage have continued to live; others have come into being. Today, Faith and Light have one thousand two hundred communities in sixty-five countries in all the continents of the world. They develop in the same way both in the industrialized countries where the structures and amenities for handicapped people are well advanced and in countries where nothing is available for such people—no schools, no laboratories, and no centers. For this reason there are communities in Sweden but also in Africa and in America. There are also communities in Japan, in Australia, and there are also very many in the Middle East (especially in Lebanon) and in the countries of Eastern Europe. It is very difficult to obtain the right material; but it is simple to establish a community. Indeed, a community needs neither finance not administration—a place can always be found in a parish, in religious buildings, or in a family. The community meets every month, and often much more frequently: handicapped people of all ages, their parents, their friends, a priest. They eat, dance, and pray together. They think about the words of Jesus together, they get to know each other, but above all else they form friendships. When one has friends, life is transformed—there is a road to follow.

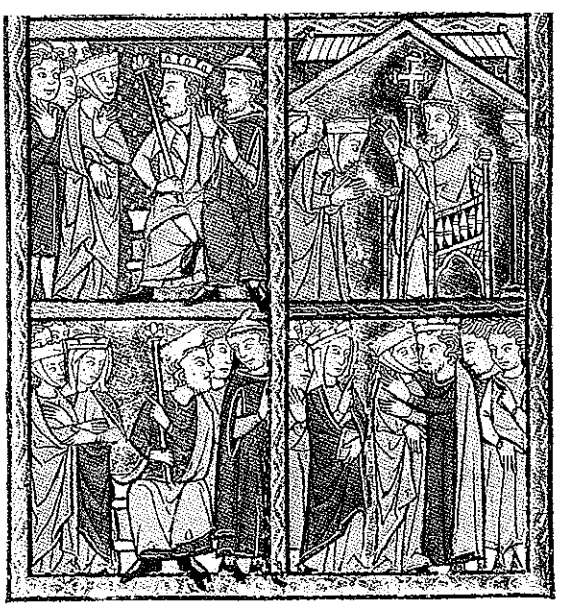
The handicapped people feel that they are the heart of the community, its cement. They find their dignity anew and rediscover a meaning to their lives The parents find out, ever more deeply, that their child is not a burden to bear, a problem to solve, but a unique treasure whose destiny is entrusted to them. They discover that there are other people who want to help them. Friends and young people often come to help and on reaching the heart of the handicapped person, his simplicity, his authenticity, and his capacity for giving, commit themselves little by little to him and with him. They discover that he can be a source of life. Faced with his weakness, they see the vulnerability of someone who should not be afraid because therein Jesus can dwell.

Eighteen months ago, at the time of the Easter celebrations, we wanted to celebrate the twentieth anniversary of Faith and Light with a " Pilgrimage towards Unity " together with representatives of the whole world. A crowd composed of all languages, races, cultures, and so forth; all intellectual levels and religious denominations. These made up an immense family in which people received from each other and gave the best of themselves; a climate of peace and tenderness which progressively conquered hotels, places to stay, shops, streets, and districts.

Way beyond our expectations, we saw, understood, and touched with our own hands how the Lord can break down barriers which separate men thanks to the bonds created by the foolish who abash the wise, and the weak who abash the strong (*1 Co* 1:27-28).

The handicapped person, in the depths of his heart, fears the tensions and the conflicts that arise and thirsts after unity. Hundreds of little flowers have bloomed—facts small in themselves, simple words which reveal the wonders of hearts and internal healing. The most important are those of parents who have received the grace of reconciliation with themselves and with their own children.

It is splendid to see so many separated brothers and sisters living side by side—Lebanese and Syrians, Poles and Russians, Francophone Belgians and Flemings—an alliance of Children loved by God which little Samuel sought to express in the following way. When he is asked if he comes from France, Belgium, Lebanon, or Martinique, he replies with sincerity in



his eyes: " Oh no! I come from Faith and Light. "

Faith and Light, born at Lourdes, has slowly spread to other Christian traditions: today there are Orthodox, Anglican, and various Protestant communities. At times there are also mixed communities which respect these different denominations But the organization of an ecumenical pilgrimage to Lourdes was a real challenge. The mother of a handicapped child who was a Protestant pastor only took part with reluctance and with her heart rather constrained, as she afterwards confided to us. Then, in humility, when she was accompanying a very handicapped person, she drank the water from the spring, she held the cross of Holy Friday, and took part in the Via Crucis. In the Methodist review, she published a moving account of her pilgrimage which certainly drew hearts much nearer than any wise reflection or theological discussion would have been able to do.

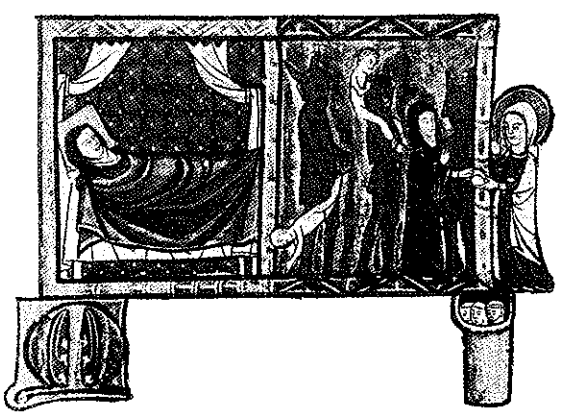
Yes, at Lourdes we understood that if we accept the reality of allowing ourselves to be touched by our handicapped brother or sister, by his thirst to be loved and to love; if we reach his heart, then something within him or her and in us is transformed, and shines around us. But how painful it is to hear of how far the handicapped person is from being welcomed into human and even Christian communities. Today, both at the center of the Faith and Light movement and at OCH, I receive letters from Africa and from the countries of Eastern and Western Europe in which parents describe their immense suffering—that of the prenatal diagnosis and of the pressure of many doctors to suppress the " nonconforming " child; that of the description of the handicap often made with great brutality; and then, during the growth of the child, the lack of structures to deal with his difficulties and possibilities. Thereafter, when he has reached adulthood, the suffering where centers are present, but where there is a shortage of educators and helpers who respect all the dimensions of the human person, help him to find a meaning to his life and to the fecundity to which each one of us is called, whether married or single.

When faced with these appeals made by handicapped people and their families, I pose a very practical question: " What can we do, we Christians, in the places where we live, so that the handicapped person—the stone that the builders reject—can rediscover the place where he should be a cornerstone and fulfill his vocation as a protagonist of society? "

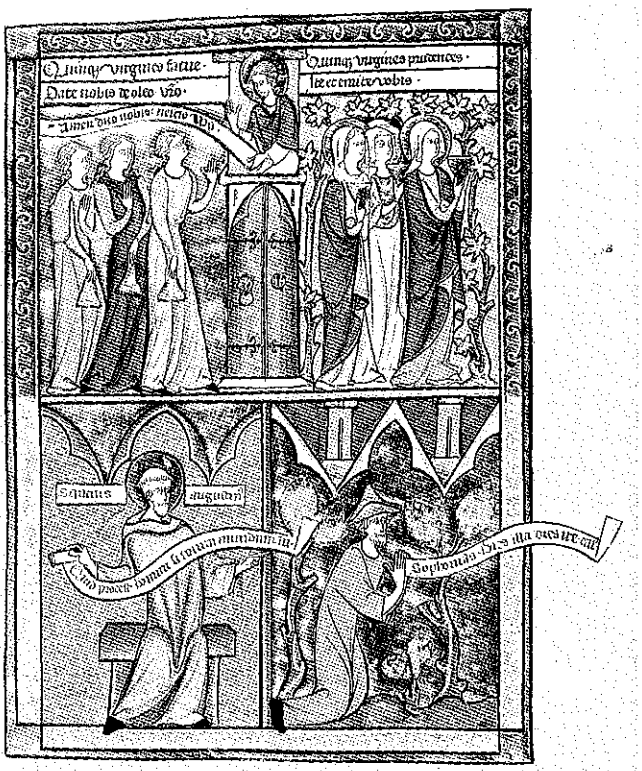
Naturally enough, there are the Faith and Light communities, the communities of the Ark, and all the other movements and associations that have been presented here. They give us hope, but above all else they give us an onward push. How can all Christians be called to listen to Christ's question: " When you give a banquet, invite the poor, the maimed, the lame, the blind "? This can be achieved, according to vocation, from the welcoming of a handicapped child to his adoption; it can be obtained through the creation of special classes in normal schools, the opening of movements to people who are deemed " different, " and their involvement in businesses. " Love is infinitely inventive " (Saint Vincent of Paul).

John Paul II invites us to build the civilization of love, and this involves a " new evangelization. " Is not the first step perhaps that of the weakest of all, with whom Christ identified? " Who ever welcomes the least of these little ones welcomes me, and who ever welcomes me welcomes him who sent me. "

MARIE-HÉLÈNE MATHIEU
Co-Founder, with Jean Vanier, of Faith and Light, Secretary General of the Christian Office for Handicapped People



Round Table



Scientific-Technological, Medical, and Pastoral Aspects of Therapy and Rehabilitation

BRUNO SILVESTRINI

Pharmacological Therapy for Handicaps

In the context of health experience, a handicap is a disadvantage for a given individual impairing his autonomy and survival capacity, thus preventing the fulfilment of a normal role in the society to which he belongs (W.H.O., 1980). Some handicaps have a genetic basis; others result from prenatal, perinatal, or postnatal conditions; others are in between, associated with a genetically transmitted predisposition to a given condition. Handicaps may consist of organic or functional defects, such as a malformation or a mental condition, and may or may not be reversible. In practice, they are represented by a variety of pathologies, from the chromosomal aberration responsible for the Down syndrome to the sequelae of a normally acute and mild condition, such as rubella. They raise, therefore, all the fundamental medical problems, but under a particularly vivid light evidencing their features without superimpositions and camouflages. The pharmacological therapy of handicaps will be examined under this general perspective, in the attempt to draw some indication of general interest

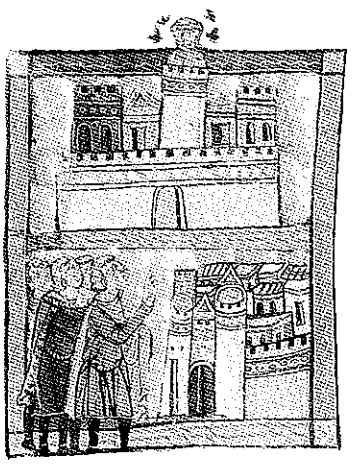
The first indication is that recently there has been a rapid and impressive progress in disease prevention and treatment. Paraphrasing a sentence that Chain (1963) wrote some years ago, I shudder at the thought that before the discovery of modern drugs I might have had to witness helplessly fetal malformations caused by maternal infections or treatments; or my children crippled with rickets or paralysed by poliomyelitis; or the devastating sequelae of syphilis, trachoma, glaucoma, or previously used drugs. Nowadays all these conditions can be easily prevented or cured. For others, such as schizophrenia, epilepsy, and blood hypertension, symptomatic treatments are available that control their most severe symptoms and permit the patients a relatively normal living standard. Their importance is shown, as an example, by the halving of stroke, which is a common cause of disability, following the introduction in medical practice of modern hypotensive agents. Also, the drug's safety is currently secured by incomparably more rigorous controls than in the past

The second indication is that these extraordinary pharmacological tools are poorly utilized. In developed countries there are still handicaps produced by conditions such as glaucoma, diabetes, hypertension, and maternal infections that could be easily diagnosed and treated. Although not strictly pertinent to this presentation, handicaps are also worth mentioning which depend on genetic factors that the parents ignore, despite the fact that they could be easily detected. These could be prevented by educational campaigns, preventive measures, and more efficient laws than the present ones; even more important, we still lack the courage to face some disturbing questions, such as the obligation of an informed and responsible procreation. Handicaps are by far more common in developing countries, where millions of persons are exposed to diseases that could be easily treated or prevented with available drugs; here, however, the organizational, economic, and social obstacles are much more complex than in developed countries.

The third indication of this analysis is that a disease cannot be really cured without clarifying its causes. The most impressive progress in pharmacological therapy has, in fact, occurred in deficiency and infectious diseases, the pathogenesis of which is well known; for all the others, including hypertension, mental, and most neurological conditions, ocular and degenerative pathologies, the avail-

able treatments are merely symptomatic.

In the beginning, basic research on diseases was performed by the academic community, and the new scientific notions were translated into therapeutic applications by the pharmaceutical industry. This separation of roles was rational and permitted the achievement of otherwise impossible results. Basic research, in fact, cannot be planned, as it generates *per se* the knowledge necessary for planning; it is unpredictable, sometimes shooting ahead, sometimes halting, despite the intensive efforts of entire generations of scientists of various countries; it lacks a direct funding mechanism, as the scientific knowledge enters into a common pool belonging to everybody; it surpasses the current schemes and notions, thus frequently leading the scientific community in to conflict with the establishment. Therefore, basic research needs freedom that is guaranteed only by public funds or by financing mechanisms unrelated to the economic value of the results of specific projects. Transforming scientific knowledge into drugs suitable for widespread use is a different task. It needs organizational capacities, highly specialized technologies, decision-marking power, promptly available economical resources, and a work team whose components must renounce their individuality; moreover, funding depends on the success of well-planned and predetermined projects and objectives. These conditions seldom occur in the academy, whereas they are typical of industry. This explains why industry, although operating in the logic of profit, has played such a decisive role in the development of modern drugs that have revolutionized the history of mankind (Silvestrini, 1986; Spiller, 1992).



In the long run, however, the balance between basic research and therapeutical applications was lost. The former was too slow in restoring the pool of scientific knowledge as soon as it was used for drug development. Moreover, there was a generalized attitude preferring practical applications rather than theoretical knowledge. A representative example is the campaign against tumors that the US Government started in the sixties. Rather than recruiting the international scientific community in basic research, preference was given to drug screening on an empirical basis. A similar trend is recognizable in most fields, from town planning to energy policy to education, in which specialization for practical activities is often preferred to culture that trains for reasoning. Solutions without a solid scientific foundation, however, are tottering and require a continuous maintainence that takes away human and economic resources from basic research. This is the state of those modern drugs that were developed by pharmaceutical industry before clarifying the causes of conditions in which they are used. It has already been stressed that these drugs are valvable, inasmuch as they provide a relief for symptoms that are painful and dangerous in themselves, i.e. epileptic seizures, blood hypertension, schizophrenic hallucinations, rheumatic inflammatory symptoms, and so on; at the same time, they are inaccurate, as they cannot address the causes of diseases which are unknown; therefore, they often present negative sideeffects. Following the thalidomide experience, drugs were submitted to more severe controls and became safer than in the past. These controls, however, require huge investments that are subtracted from other basic research. There was also another phenomenon that deserves careful attention. If a drug is introduced into therapeutics without a solid scientific background, the latter must be constructed later. Basic research, therefore, was diverted from medical conditions to drugs, and an impressive body of knowledge was derived from their study. As Tomatis (1985) notes, modern drugs are often discovered and studied by scientists who have never seen a patient. This body of knowledge reflects the specific features of symptomatic drugs, rather than the core causes of diseases that they influence. Thus the notion that the study of drugs could provide an insight into medical conditions often proved misleading.

In my opinion, the impasse of pharmacological research in handicaps and other conditions still lacking etiologic treatments depends much more on this imbalance between basic research and practical applications, rather than on the fact that the above medical conditions are moredifficult than others. Presently available research instruments, in fact, are so potent that they can reach and explore any biological event down to its molecular level.

I would like to conclude this talk with a few observations on the responsibility of the scientific community in the two above-mentioned phenomena: the poor utilisation of presently available drugs and the relative lack of basic research in drug development. Many scientists believe that their duty is to accumulate the knowledge that provides the foundation for human progress. Others, instead, operate to satisfy the specific needs of man, at the service of industry and government institutions having this specific duty. In my opinion, this second condition is incompatible with the fundamental requirement of science, which is freedom. Scientists,

however, have the same responsibility as any other citizen with regard to their country and, more generally speaking, the surronding world. When man's needs become pressing, they must leave their ivory tower and contribute to satisfying these needs by committing themselves not only at a cultural, but also political and practical level. In that moment they cease to be scientists to assume a different, but equally important role.

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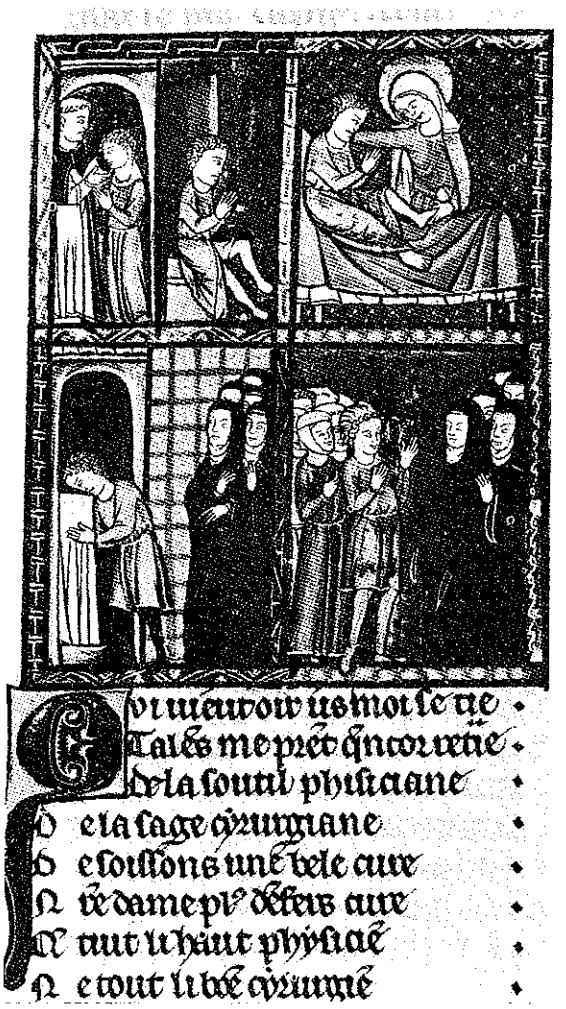

FERRUCCIO ANTONELLI

Psychotherapy for Disabled People

The insertion of psychotherapy in to a program of rehabilitation for disabled people can provoke a certain perplexity on the part of public opinion. Indeed, public opinion has a somewhat reductionist concept of psychotherapy and goes almost so far as to identify it with psychoanalysis.

It is obvious that when one speaks about psychotherapy for disabled people one is not talking about making them lie down on a psychoanalyst's couch, even though this possibility cannot be completely excluded. Ten years ago, at Rome's Eliseo Theater, an (absolutely new) work by Tom Kempinski, entitled " Two Voices for One Person, " was performed. Only two characters were in the play—a psychoanalyst (Sergio Graziani) and a lady (Rossella Falk), the latter in a wheelchair. She was a violinist who had been told at the age of thirty-five that she suffered from sclerosis. The need to change her whole existence and to embark upon new lifestyles had led her to call upon the help of a technician of the psyche.

Psychotherapy is one of the four ways by which health workers can treat a patient. The others are surgery, the prescription of drugs and medicines, and the use of physiotherapy.

By psychotherapy one means " all those psychological instruments which can be used with a therapeutic aim in mind " (Guyotat).

With regard to psychotherapy for disabled people, these instruments take three distinct forms: the individual, the social, and the familial.

Individual Instruments

The disabled person, whatever his handicap may be, is a human being with a crisis of identity. He is disturbed (and at times overwhelmed) by a painful sense of alienation and deprivation. His reality is very hard for him to accept. His reactions take various forms: from desperation to anger, from depression to aggressiveness, from feeling the victim to pretentiousness. It never rains but it pours. Added to the affliction of being disabled there is a psychopathology which should also be treated.

One can with confidence maintain that every disabled person can take advantage of a psychotherapy of support, whatever the kind of psychic or physical handicap he might have and whatever the stage in life from which it stemmed (birth, childhood, or accident).

Amongst the various techniques, special stress should be laid upon cognitive-behavioral, relational, and short-term psychotherapy.

When the object of this treatment is a handicapped person the psychotherapeutic treatment should be rather modified. The focus is not the awareness of unconscious conflicts (insight), nor liberation from a symptom (e.g., a phobia), but the identification of the residual personality, or the personality which has remained intact. This has as its aim the strengthening of the personality with a view to re-adaptation and social integration.

Another important aspect is the relationship between the psychologist and the patient. The former should be directive, pedagogic, and full of praise. This is done not to take the place of the parents of the handicapped person but to optimize his behavior. Thus there is always a positive attitude, and things are seen and done in a way which can be understood by the disabled person, especially if he suffers from a psychic handicap (e.g., the Down syndrome).

The important thing is that the handicapped person is fully aware of the fact that he can count upon the person practicing the therapy to help with every kind of problem—he thus feels unburdened of the difficulty of solving it himself. To put it another way: " I do not know what to do but it does not matter; I will ask him and he will give me advice. " Such are the essential elements for psychotherapeutic activity which is termed " counselling " and " problem solving "

Social Instruments

Ever since the abolition of the differential classification of handicapped people an equality of rights and respect has been upheld. However, beyond a formal equalization of status there remains a substantial difference at the level of facts.

For this reason the disabled person should have opportunities of a spatial and temporal character to live with those who are also handicapped so that he will experience the pleasure of being able *to do something better than somebody else* and to do it in a way which is better than he expected.

Here are certain psychotherapeutic instruments which are reserved, in particular, for neuropsychically handicapped people such as spastics and Down subjects, especially if

they are undergoing childhood or adolescence.

Occupational therapy in the drawing, painting, pottery, leather, sculpture, carpentry, sowing, or cooking workshops.

Play therapy—all the endless games of nursery and elementary school and, in addition, singing, dancing, and acting.

Psychomotor and motor rehabilitation—this is something more than medical gymnastics or physiotherapy, which have the aim of canceling, through entertainment, the boredom of repetitive gestures. Here one is talking about running, jumping, balance exercises, somersaults on mattresses, swings, climbing, slides, and so forth.

Horse therapy—the new use of the horse in being of service to man.

Reality Orientation Therapy (ROT)—a therapy for elderly people who are disoriented because of Alzheimer's disease or similar conditions. Described by Taulbee and Falsom, this therapy is practiced widely in geriatric institutes. It involves the provision of repeated information which is designed to help and to achieve orientation, and to reinforce the behavior which is thus oriented. It is closely linked to the techniques of validation therapy (Feil), *life review*, and *environmental modification*.

Sports therapy deserves separate treatment. In Italy the creator of sports for paraplegics was the late Antonio Maglio, who when he ran the Ostia Paraplegic Center, loaded his patients onto a boat and literally tossed them into the sea to teach them to swim. People become paraplegics today only as a result of trauma, but before polio was overcome, such patients were numerous and represented a major social problem—young people confined to bed without hope on a tragic waiting list made more painful by bed sores. Today paraplegics are prepared for sports activities in wheelchairs and themselves choose the discipline: basketball, fencing, archery, light athletics, table tennis, and so on. The effect is considerable—not only on the body, but above all on the spirit. The alert, competitive atmosphere of sports restores identity, security, incentives, and even enthusiasm. Sports mean competition, but also training, travel, social relations, and commitment. And not just for athletes, but also for the other disabled, who participate intensively and collectively, offering every kind of assistance and authentic support. Since disabled sports clubs arise at specialized facilities, they are at once the fruit and the fruition of the whole community.

Sports activities also exist for other handicapped people: races, skiing, bicycling, soccer, and volleyball for the blind and deaf; horseback riding for Down's victims; light athletics for amputees, spastics, and the psychically disabled; and even for a category of the handicapped so hard to classify as to be termed " others. "

Sports for the disabled are worldwide. There re national and international championships, and even special Olympics. A million disabled people took part in the last Special Olympics. In Italy there are 10,000 members of the FISD.

Disabled atheltes are not " inferiors allowed to participate " (as Guicciardi and Salvini rightly point out, but athletes in the true sense of the word. Maglio would say to his paraplegics, " No one can take away your unaltered dignity even in an externally altered physical state. "

These athletes do not want pity-they hate all forms of commiseration. They experience their sport not as physioterapy or psychoterapy, but in the completeness of play and competition comprising sports culture.

To grasp this conception better, let us recall the famous movie *Rain Man*, with Dustin Hoffman, the autistic person who with his exceptional gifts of memory at first prompts surprise and sympathy, but who, if engaged in competition with a someone like him, would turn onlookers into real fans, for he would no longer be a circus curiosity, but a true competitor.

Sports for the disabled are not just rehabilitation—they are rebirth.

There are even some disabled people in a position to compete on an equal basis with the normal—and at a topfight level.

The Italian team at the last Olympics included a deaf-mute diver and a skier with muscular dystrophy in one arm.

Family Instruments

Recently another instrument of psychotherapeutic intervention was identified in addition to the individual and social ones: the examination and support of the family atmosphere.

In 1962 English psychiatrists (Brown *et al.*) brought out the influence of the family on relapses and social integration of schizophrenics. The term " expressed emotion " (EE) was oined as applicable to all the disabled.

EE, or emotional temperature within the family, may be mesasured by a structured interview of about an hour, the Camberwell Family Interview (CFI), which is conducted with every relative living with the disabled person. The test includes five numerical scales defined as follows.

— *Criticism*: frequent expressions of disapproval or resentment.

— *Positive remarks*; spontaneous expressions of approval and satisfaction.

— *Emotional overinvolvement*: excessive dedication, self-sacrifice, overprotection, and control, and sometimes symbiosis and overidentification.

— *Hostility*: a generalized, profound negative attitude of disapproval and intolerance towards the disabled as such, even before criticizing behavior.

— *Warmth*: an attitude of real interest in the disabled relative.

If one or more family members living with the disabled person surpass the thresholds established empirically for emotional overinvolvement, criticism, or both, the family is termed " high EE, " with serious harm to the disabled, especially if in touch with relatives more than 35 hours a week.

On the other hand, " low EE " relatives show greater understanding and respect and tend to legitimize the handicap, not criticizing its manifestations as " voluntary, " helping the disabled to reinforce self-esteem, growth, independence, sociability, and planning.

The concept of EE is a real " clinical construct " enabling psychologists to point out the families

at risk and them instruct them to live with the disabled (Anderson) and reach an optimal level of management (Cazzullo), guiding them with problem-sloving strategies (Falloon) and psychoeducational treatments.

My experience with the Don Orione organization confirms the disabled's speedy and considerable individual and social progress when they enter—even on a part-time basis—facilities offering occupational or psychomotor therapy (sports are the best kind).

My experience further demonstrates the joyous satisfaction of disabled young people and adults when they manage to live on their own, drive their car (with the necessary modifications), fall in love, and get married.

All of this backs up the advantage of early separation from the family—indicating that high—EE families are quite numerous. Perhaps all rre, since at least one relative (generally, the mother) proves to be emotionally overinvolved.

From this concluding observation it follows that in the future—a future that is already beginning—the priority concerne of psychoterapy for the disabled should be their family ecosystem.

Sports therapy deserves separate attention. In Italy the person who began sports for paraplegics was the much missed t is certainly not the passive acceptance of her handicap. She dedicates herself to society and seeks to improve the conditions of life of disabled and sick people.

These people are responsible. For example, they must be able to move themselves around easily, even if they are paraplegic. These very human attempts and efforts are at the root of the Christian life of our friend. She makes them in a reflection of the true light of Christ. She wants to make her brothers and sisters capable of their same reflection. In the Brotherhood of her country she becomes the national director of the education committee.

This testimony shows just how much those values which our modern world holds so dear must be relativized—that is, related to what constitutes the real center of that form of human life which Jesus called upon us to lead. Let us listen to St Paul when he tells us about the fruits of the Spirit. They are: love, joy, peace, patience, kindness, generosity, forbearance, gentleness, faith, courtesy, temperateness, and purity (*Ga* 5).

Our friend seems really to have, *in truth*, understood St Paul. On the other hand it is only this truth that should be presented, before all others, to our brothers and sisters who are suffering and downcast, who are exploited and forgotten! The experience of the African Brotherhoods, for example, gives us in this regard a very powerful testimony. A group in Zaire, another in Madagascar—areas in which one does not eat in abundance—nevertheless manage to save enough food to go and feed prisoners who could well die of hunger. A large number of groups in Latin America are strongly committed to eliminating illiteracy. In this immense continent one has to fight for everything that will contribute to the freedom of the poor.

Many examples could be given of these examples of witness which are to be found in all the four corners of the earth. In essential terms, they do nothing else but give life to witness on a grand scale—that of the Intercontinental Christian Brotherhood of Sick and Handicapped People, and that of a responsibility necessary to the life of the world and the Church expressed towards those who seem to be the weakest and the most limited amongst men.

Indeed, what would happen to the world of men if *effective responsibility* for things were *only* in the hands of the powerful, the rich, and the healthy? True values would be hidden and forgotten by everybody. What can one say about these values? Deep human strength can overcome apparent weakness. Every person can discover what is inside them in so much as he can *be committed* without being *merely helped*. Every person has the same rights regarding human life: the right to education, to work, and to health. Every person has, *at base*, the same duties, and they are part of a *real responsibility* towards *serving* the world.

Finally, what, indeed, would become of our Church if responsibility was simply a question for the strong; if only the rich could really give to other people? The Church would, in that case, be more *dominator than handmaiden*. The Brotherhoods of Africa or Latin America are today, in an especial way, the testimonies to these Gospel truths —Jesus came to heal, not to abandon his disciples to illness. He came to integrate men into his Church, in so much as we *are all* members of a *responsible people*. Jesus did not come to call upon men to take their sufferings to Heaven. His Father sent him to share the suffering and the death of men, to *fight together with them* until the Resurrection. This is the message that all the handicapped and sick people of the earth expect from our Church. This is the message that the Brotherhood, in the Church, wants to send to all men.

Is this not perhaps the message that St Paul writes to the Corinthians: " God has chosen what the world holds weak, so as to abash the strong "? (*1 Co* 1:27).

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NAOICHI TSUYAMA

Surgical Treatment

It is really a dreadful fact that we are confronting a rapid increase in the population with disabilities. More than half a billion of the world population is said to be people with disabilities.

Our statistics in Japan show this fact as well. At the present moment there are 2.4 million people with physical disabilities among the 120 million in the nation and the rate increases by 20% every five years.

These people must live the rest of their life with disabilities and handicaps.

Needless to say, implementation of preventive measures is of the utmost importance. For example, we started nationwide poliomyelitis vaccinization on a compulsory basis in 1961 and this resulted in a dramatic reduction of the polio victims.

Before this we had about 3000 victims every year but this became practically zero after two years. This means if we had started five years earlier, we could have saved nearly fifteen thousand polio disabled.

Then how can surgery be of any help for these serious problems?

Thanks to the development of various diagnostic methods, effective anti-infectious drugs, biocompatible materials, a deeper understanding of biomechanics, and microsurgical techniques, recent advances in the field of surgical treatment are quite remarkable.

For example, artificial joint replacement is now routine in orthopaedics. Destroyed or deteriorated joints can be replaced by an artificial knee, hip, ankle, shoulder, elbow, or wrist, and and these joints can be reconstructed to give useful limb functions.

But we must not forget, too, that execcive enthusiasm with lighthearted trial and error or the commercial strategy of constant model change is also proroking other possibilities of inducing devastating failures which will take place later on.

Surgeons must be aware of that and be cautious enough to perform this kind of surgery only when it is really indicated. Too much mechanization is contradicting the biological natural self-cure process inborn in a living body.

There are quite a number of ways of surgical reconstruction for physical disabilities, including osteotomy, arhrodesis, tendon or muscle transfers, and their combinations. Just for example, severe disability of the knee due to loss of knee extensors can be solved by a simple knee recurvation osteotomy which normalizes the weight-bearing alignment.

At the same time we must know how wonderful a plasticity or convertibility does exist in our neuromuscular control system.

We produced many unhappy babies having upper limb deformities caused by an administration of thalidomide in early the 1960's. This drug was so effective in stopping pregnant mothers' hyperemetic suffering that it became very popular in Japan, but this drug had noxious effects in distorting the normal development of foetal upper limbs and in worst cases resulted in complete absence of the bilateral upper limbs. Realizing their responsibility for permitting this drug on the market, the Ministry of Public Health of the Japanese Government ordered us to develop a mechanized motor-

driven, very costly artificial limb. However, 20 years later no body is using this sophisticated prosthosis, because there is no sensory feedback and it cannot merge with one's own body image.

Instead, they are doing every activity of daily living by using their feet and toes, including writing, drawing, cooking, combing, telephone calling and even driving a modified motorcar.

This plasticity of the neuromuscular control system is the basis of many reconstructive surgeries, particularly of muscle or tendon transfers or of nerve-crossing procedures.

Another example is as follows.

Motorcycle accidents are very common in Japan, particularly among youngsters, because of motorcycle fever at home. In very severe cases, all the cervical spinal nerve roots (C5-Th1) innervating the whole upper limb can be pulled away from the spinal cord.

For this kind of irreparable avulsion of the whole brachial plexus, we are doing intercostal nerve crossing, mainly Th3 and Th4 to the musculocutaneaous nerve, with the intention of regaining elbow flexion and at times wrist extension. The results have been much more satisfactory than we expected when we started it as a last resort. Involuntary respiratory activities gradually disappear and useful volitional control can be recovered.

These facts mean that the innervation mode in Penfield's precentral motor-cortex map is not a fixed and rigid one but can be modifiable, flexible, and convertible, showing a remarkable plasticity.

Then what is the mechanism of this kind of plasticity? The followings are suggested at the present moment: (1) increase of conduction substance, (2) increase or enlargement of synapses, (3) atavistic reutilization of the older system used in the past, (4) development of new connections and networks through sprouting, (5) enlargement of the motor unity or increase of the innervation ratio, (6) improvement of muscular efficiency, and (7) others.

These natural processes teach us that our living body does have a wonderful ability for self-repair and also that surgical treatment is nothing but assisting this inborn natural self-cure ability.

This reminds us of Hippocrates' teaching, " Medicus curat, natura sanat "

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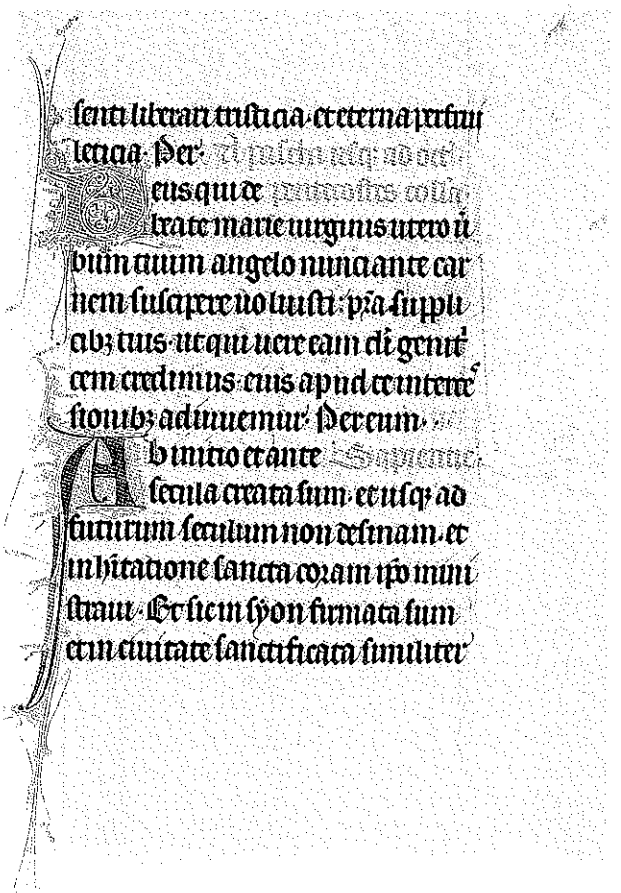


JOSEPH E MURRAY

The Role of Plastic Surgery

The topic of this conference, as stated in the letter of invitation, is based on a " setting of *hope*, from the perspective of anthropological, scientific, clinical, ethical, juridical, and sociological points of view. " This concern derives from the Church's traditional high priority to serve all those who suffer in body and in spirit. The Church's motive is to contribute to the elimination of, or at least to the utmost possible degree, to the control of the causes of disability which attack such a large part of the human community.

I thank you for the invitation to participate in this remarkable conference with so many highly motivated health care workers from every continent. A brief outline of my professional background will help to place my subsequent remarks in perspective.

Graduating from medical school during World War II, I was randomly assigned to a Plastic Surgical Hospital in Valley Forge, Pennsylvania, USA, where we cared for thousands of battle casualties from the African, European, and Pacific theaters of war. This military experience in plastic and reconstructive surgery was a decisive influence in my medical career by stimulating my professional interest both in transplantation biology and in physical deformity.

My clinical professional life has been involved in plastic and reconstructive surgery with a special interest in the treatment of facial deformities. My major research, kidney transplantation, was an extension of this general interest in surgical reconstruction. Regarding transplantation biology, the lives of battle casualties suffering with massive burns could be saved by transplanting skin grafts from cadavers as temporary skin dressings. Although these " foreign " skin grafts were ultimately destroyed by the patient's immunological system, they could be lifesaving by controlling infection and fluid loss.

Returning to Brigham Hospital and Harvard Medical School in Boston after the war, as a research project I pursued the study of transplantation immunology in man and laboratory animals, i.e. mice, rats, rabbits, sheep, dogs, and horses. These studies ultimately led to the first successful organ transplants in man, for which I received The Nobel Prize for Medicine in 1990.

My other interest originating in military service, the reconstruction of physical deformity, has led to the use of innovative surgical operations to repair the face, skull, hand, trunk, and extremities. At Valley Forge General Hospital we cared for hundreds of blind patients, as well as wounded German and Italian Prisoners-of-War.

Often patients developed an unspoken anxiety as the time to leave the hospital approached, a worry about adjusting to the " normal " world. We empathized with their physical, mental, and spiritual concerns. We have maintained contact with some of these former patients, and over the years their lives have been a strong positive influence on me and my family.

In the surgical care of disabled persons the scientific, clinical, ethical, and sociological aspects are overlapping and intertwined. Facial deformities fall into four general categories:

1. Deformities or defects caused by *genetic* or environmental factors, usually detected at birth. Mental retardation may or may not be associated.

2. *Traumatic injuries* may occur throughout life; common causes are burns, motor vehicle and industrial accidents, and, of course, warfare.

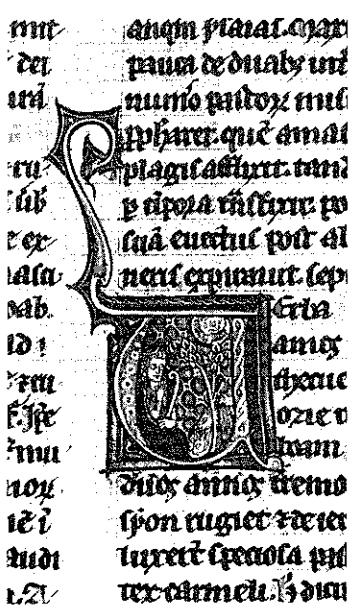
3. Cancer of the head and neck and its treatment, may produce severe deformities.

4. *Cosmetic* defects that in some patients can produce emotional and

psychological states incompatible with balanced living.

The patient's psychological attitudes play a major role in the ultimate outcome. The mental reactions of denial, acceptance, pity, guilt or reclusiveness are essentially spiritual in nature and are pivotal in the success or failure of therapy. Regardless of cause of the deformity and mental status of the patient, some patients adjust and respond to treatment with understanding and appreciation. Others, often with less severe defects, succumb to self-pity and complaining, thus creating an even greater burden to family and society.

Physicians have a crucial responsibility in the diagnosis of genetic facially disfigured patients. We must be careful and avoid the pitfall of diagnosing mental impairment on appearance alone. If we establish a self-fulfilling prophecy, "If you look retarded, you are retarded," parents and teachers may lower their expectancy and deprive the individual of proper physical and intellectual stimuli. If this occurs, patient, family, and society all suffer; the handicapped



may remain entrapped within their physical confinement, unable to utilize their capabilities to their fullest.

Many patients have been mistakenly considered to be intellectually retarded and thus confined to mental institutions, only to be discovered later to have full cognitive potential. A drooling patient, with a protruding tongue, impaired speech and hearing, may have normal intelligence that is masked and confined by physical factors.

Handicapped persons deserve every possible help. To give them extra assistance is not only right and just, it is practical and makes good economic sense. It can change a person from a tax burden into a taxpayer.

Preparation for this talk has sharpened my insight into the vast differences in health care between western societies and developing countries. Although in the past I have had personal experience in the care and surgical treatment of patients on all continents, today I am shaken by the reality of the worldwide differences in standards of care and treatment. It is unsettling and disturbing for me to be a surgeon performing extraordinarily complex cranial-facial reconstructive operations, knowing that thousands of other patients just as deserving are destined to live and tolerate their condition without possibility of help.

Indications for surgery fall into three broad categories:

(i) life and death situations, e.g. for cancer or when a blood vessel or viscus bursts, blocks, or gets infected; (ii) restoration of function, e.g. broken bones, pain on walking or eating, burdensome tumors; and (iii) psychological and cosmetic reasons, i.e. ugly birthmark, deformed ears, visible scarring.

It is difficult to apply identical standards of care and treatment for the disabled in all societies. I will document selected patients to illustrate some clinical problems together with results following reconstructive facial surgery. This background may serve as a framework for our overall considerations as we collectively search for an optimal course of action for disabled persons in society.

Cleft lip and palate, the most common facial birth defect, are almost never life endangering. Nutrition can usually be maintained, although dentition and speech frequently require treatment.

Leprosy, an infectious disease of low virulence, primarily involves peripheral nerves. It still is widely prevalent. Surgery can help heal open sores of the body and extremities, as well as improve the function of hands and eyelids. But surprisingly, patients also seek correction of their missing eyebrows. Although these cause no symptoms, they are a visibly obvious stigma of the disease and thus extremely undesirable to the patient. The indication for eyebrow replacement is obviously psychological and cosmetic, but no less justifiable.

Postoperative rehabilatation in leprosy is critical because the patient must be taught about the perpetual care and protection of his insensate skin. He must protect himself from himself. He should whenever possible be taught skills by which he can earn a living and thus have a gainful means for economic support.

Hemifacial microsomia, the second most common congenital facial deformity, has many different manifestations. This multivariable condition is characterized by one or all of the following: unilateral underdevelopment of the upper and lower jaws, deformed or misplaced ears, partial paralysis of cranial nerves, and deficiency of facial soft tissue. These patients have normal intelligence. Treatment is complex and varies with the severity of the facial distortion and age of the patient.

Nature plays strange tricks with human embryology. Each of us has developed from a single cell formed from the fusion of an ovum and a spermatozoa. After about six weeks in utero, this single cell develops into a full embryo with most of the physical features of a full term baby. How undifferenciated cells find their way around in the dark and fluid environment of the uterus to form all the different organs and tissues, e.g. brain, toes, heart, hair, is the core of current molecular and cellular biology.

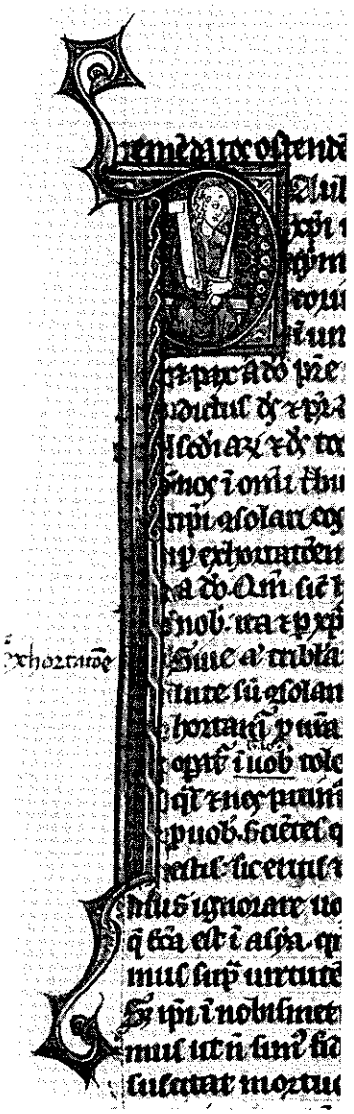
As plastic surgeons we are often called upon to treat nature's misadventures. The "double mouth" child is one such example, fortunately a rare and treatable condition. This status is compatible with

life and produces no functional loss. Nevertheless, no one anywhere would withhold treatment for this condition. The reasons for operating are psychological and esthetic. Although the result following surgery in one case was satisfactory, and the patient and family were overjoyed, much better restoration of the mandible and teeth could have been obtained with additional surgical and orthodontic care. Unfortunately this was not possible in this instance.

Malignant tumors, although more common in older adults, can occur at all ages. If the lesion is on the face, the problem is complicated not only by the appearance of the tumor but also by possible additional disfigurement from treatment, i.e. surgery, X-ray therapy, chemotherapy. When tumors occur on the face of an infant or child, decision-making becomes even more complex because anatomical and psychological growth vary so much in growing children.

A major group of congenital handicapping deformities are cranial and facial synostoses, i.e. failures of growth of the skull and facial bones. They have been known throughout history and frequently are associated with mental impairment of varying degrees. If the skull does not expand and grow normally, the underlying brain may be compressed, thus adding to the mental problem. Treatment for the past 40 years has consisted of removing parts of the restraining skull bones to optimize brain growth. Within the past 20 years, new surgical approaches, pioneered by the great French surgeon, Paul Tessier, have been used to correct the associated facial and orbital deformities as well.

The causes for many birth defects are still unknown. Genetic and environmental factors are cited as the usual explanations, but often they are merely descriptive terms that hide our ignorance. Some birth defects may be caused by fragments of the amniotic contents, so-called "amniotic bands," that become entwined in the developing fetus, usually around the hands or legs. Clinicians caring for patients with birth defects have an opportunity and responsibility to observe, record, and study these "experiments of nature." Medical progress through the years has been made by curious physicians who have attended some of these patients, often under rather primitive conditions.



Body image is a real entity. Each of us has an inner concept of ourself. It is not a composite photo of our many physical attributes; it does not physically reside in any specific part of our anatomy, our brain, heart, intestines, or genitalia. It is the summation of our entire being, developed by input from our physical senses and modified by our intellectual, emotional, and spiritual experiences.

The normal and disabled child follow distinctly different pathways of development of their body image. The normal child's expands and grows as milestones of care and education proceed, leading ultimately to a world of opportunity. In contrast, the handicapped may consciously or subliminally be rebuffed and discounted during the critical phases of development, leading to a restricted, often reclusive, lifestyle.

In dealing with disabled or handicapped persons it is helpful, if not mandatory, that we keep clearly in focus our priorities of treatment. We are not treating a "cleft lip"; we are treating "a patient with a cleft lip." In life, persons are judged more by appearance than by any other physical characteristic. Try to imagine how differently each of us would have developed had we been born with an extensive discolored birthmark, displaced eyes and orbits, withered ears, a twisted facial skeleton, asymmetrical or absent nose, or saliva-drooling from a protruded tongue.

Dr. Will Mayo, the founder of the famed Mayo Clinic, said it well, "It is the divine right of man to look human." John Adams, the second president of USA, put human priorities in place by establishing law and the legal profession as the foundation for a workable society, followed by the roles of the geographers, carpenters, navigators, and other builders of society. He placed the fine arts, music, painting, literature at the pinnacle of man's achievement, tacitly recognizing the outstanding role of the mind and spirit of man.

The life of one patient can serve as a fitting summary for my presen-

tation. Charles Wood was a penniless orphan from the deep south of the USA. As a child he loved airplanes. He joined the Canadian Air Force before the USA became involved in World War II. After the Japanese bombed Pearl Harbor, he joined the USA Airforce and was decorated for service in combat in Africa and Europe. After reassignment to the USA to teach pilot training, he volunteered for duty in the Pacific. He was assigned to duty flying military supplies from Burma into China over the Himalaya Mountains. While training a pilot, the plane crashed, and Charles sustained severe burns to his hands and face. After hovering between life and death for several weeks, he was flown back to the USA via India, Arabia, Northern Africa, South America, and finally to our hospital in Pennsylvania. After several months and many operations, some of them using skin grafts from cadaver donors, we were able to close his burned wounds. We were left with the overwhelming task of restoring his mouth, nose, eyelids, and hands. After 2 years and some 30 operations he was healed well enough to be discharged. He returned to his home in Alabama and, realizing that returning veterans would be needing housing, he borrowed money to built homes. He reinvested all his money into more homes. Then he bought a television station, at that time a new industry. Soon he had a television network over much of the USA. Today he is a multimillionaire and serves as a philanthropist for many communities. He still looks like a " man from Mars " without ears, a nose made from his arm, and finger-like digits on his hands made from remnants of the palms of both hands.

Today, if asked about his " handicaps, " he claims they are assets. " No one ever forgets me. Sometimes competitors underestimate my ability, and so I have an advantage over them " His spirit has triumphed over what many might consider overwhelming disability.

To summarize, in treating handicapped or disabled persons, remember primarily that they are human beings, with the same hopes, fears, ideals, and aspirations as everyone Whatever disabilities and burdens they carry, we are obligated to help lighten the load.

No one person or group can do it alone, although Mother Theresa has come as close as anyone. The theme of this conference is hope. With trust, help, and guidance from Our Creator, each of us in our daily living can make a difference.

Professor JOSEPH E. MURRAY
Nobel Prize Winner for Medicine, USA

AMICO BIGNAMI

The Status of Research on the Regeneration of the Nervous System

1. We are dealing with the riddle of central nervous system (CNS) regeneration. If the peripheral branch of a sensory neuron is cut, the axon will regenerate and the same is tue for the central branch outside the spinal cord. If the central branch is cut within the spinal cord, regeneration is at most abortive

The most common reaction of the astrocyte to injury is the accumulation of 10-nanometer (intermediate) cytoplasmic filaments, a phenomenon termed fibrillary gliosis by the pathologist. In fact, our studies on astrocyte filaments were mainly motivated by the hypothesis that the glial scar war the barrier to axonal growth. When we started our investigations, little was known on the biochemistry of intermediate filaments in astrocytes and other cells. perhaps the most interesting results of the studies conducted in several laboratorias, is that the proteins forming the filaments are tissue specific and thus provide immunohistological markers to identify the cells forming the main tissues of the body. As a specific example, the protein forming glial filaments (GFAP) has revolutionized the study of astrocyte function since it has allowed the identification of these cells in tissue culture.

The availability of a cell specific marker to identify astrocytes allowed a reinvestigation of the role of the glial scar in nerve regeneration. Two lines of evidence appeared incompatible with the hypothesis that the glial scar prevents axonal regeneration

If the proximal branch of a sensory neuron is cut outside the spinal cord, the axon will regenerate. However, regeneration stops at

the PNS-CNS junction even if the spinal cord itself has not been injured. In other words, regenerating axons fail to penetrate into the non-injured spinal cord even in the absence of a glial scar.

2. It is now well established that peripheral nerve grafta implanted into the brain become innervated. In order to enter the graft, axons must grow through the glial scar resulting from the operation.

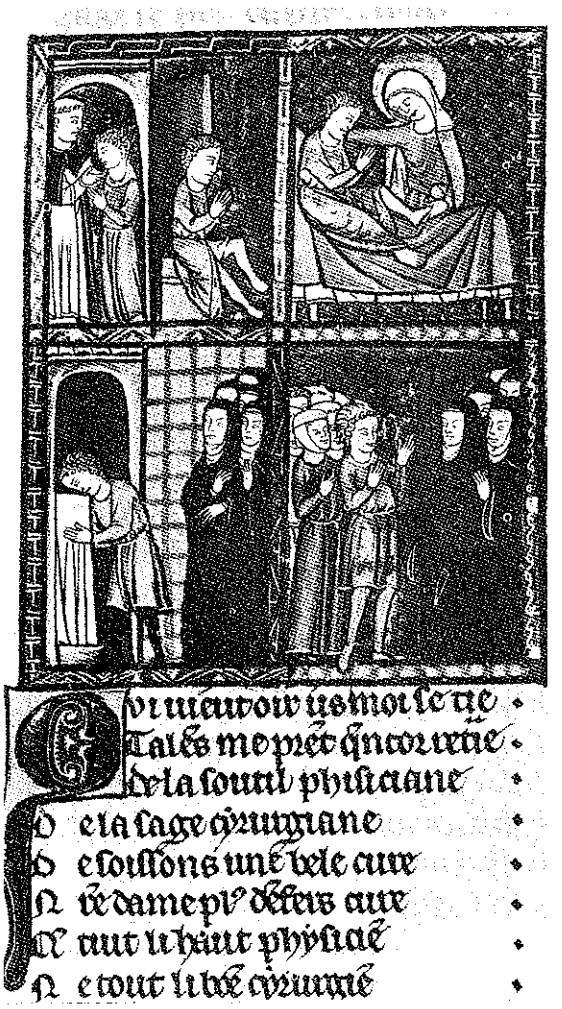
If the glial scar is not an insuperable barrier, the possibility may be considered that normal CNS tissue may contain factors which are inhibitory for axonal growth. If the nerve fibers are severed as in spinal cord injury, the axons rapidly disappear but myelin persists for long periods of time. According to Schwab and coworkers at the University of Zurich, the inhibitory factors are normal myelin components. Another possibility is that the extracellular matrix is partly responsible for the differences observed between CNS and peripheral nerve with respect to nerve regeneration. As for glial filaments, little was known on brain extracellular matrix when we started our investigations. In fact, it is widely believed that there is no extracellular matrix in the brain and this in view of the fact that brain extracellular space constituting 17-20% of brain volume appears empty by electron microscopy. Later in my talk I hop I will be able to give an explanation for this surprising phenomenon.

Cartilage is one of the tissues in the body less supportive of exogeneous growth including metastatic tumors and blood vessels. In cartilage extracellular matrix, aggregates formed by proteoglycans and

hyaluronic acid are stabilized by the link protein, another hyaluronate-binding protein. The first question we asked is whether proteins with the same properties could also be found in the brain. We were thus able to isolate from the brain in milligram quantities, two hyaluronate-binding proteins, a small glycoprotein (60 kilodalton) and a large proteoglycan (365 kilodalton). An important finding was that these proteins not only bind hyaluronate but show great similarity to cartilage proteins at the structural (amino acid sequence) level. These findings may explain why brain extracellular space appears empty by electron microscopy. Hyaluronic acid is very soluble in aqueous fixatives and when hyaluronic acid is dissolved, hyaluronate-binding proteins are also solubilized.

Only recently we were able to fix satisfactorly this matrix for electron microscopic studies. It remains to be seen whether an extracellular matrix is in fact inhibitory for axonal growth. An experimental approach may be possible in that the matrix disappears from the brain following hyaluronidase injection.

Professor AMICO BIGNAMI, M.D.
Professor of Neuropathology at Harvard Medical School, Boston, USA



JOHN V. BASMAJAN

Medical Aspects of Rehabilitation

Until recent years, confusion reigned about all the words and ideas tossed about in medical rehabilitation. What precisely did each one mean? Patients, families, the many therapeutic specialties, government and private agencies, and all the learned professions and vocations had not settled on universally accepted and precise definitions. The processes that ranged from the initiating illnesses and injuries to the ultimate levels of individual and/or general outcomes had multiple and misleading names.

In my half-century on this medical and scientific front, I have witnessed some erosion of the mystery, but much more survives to severely handicap our efforts. Improvement and wider acceptance of a common language of rehabilitation is imperative to permit a fresh recharging of our batteries for the next series of forward thrusts. Otherwise, we will become bogged down. Elsewhere, I have pleaded for our concerted effort and further refinement of definitions, classifications, and natural history (1)

Definitions and Classification

We should all be grateful for the work more than a decade ago of the World Health Organization (WHO) Task Force chaired by Dr. Phillip H. N. Wood of Manchester. Their International Classification of Impairments, Disabilities, and Handicaps (2) was both a landmark and a banner. It led to intelligent dialogue and action on many fronts, including further refinement and enhancement by others. Boiled down to its

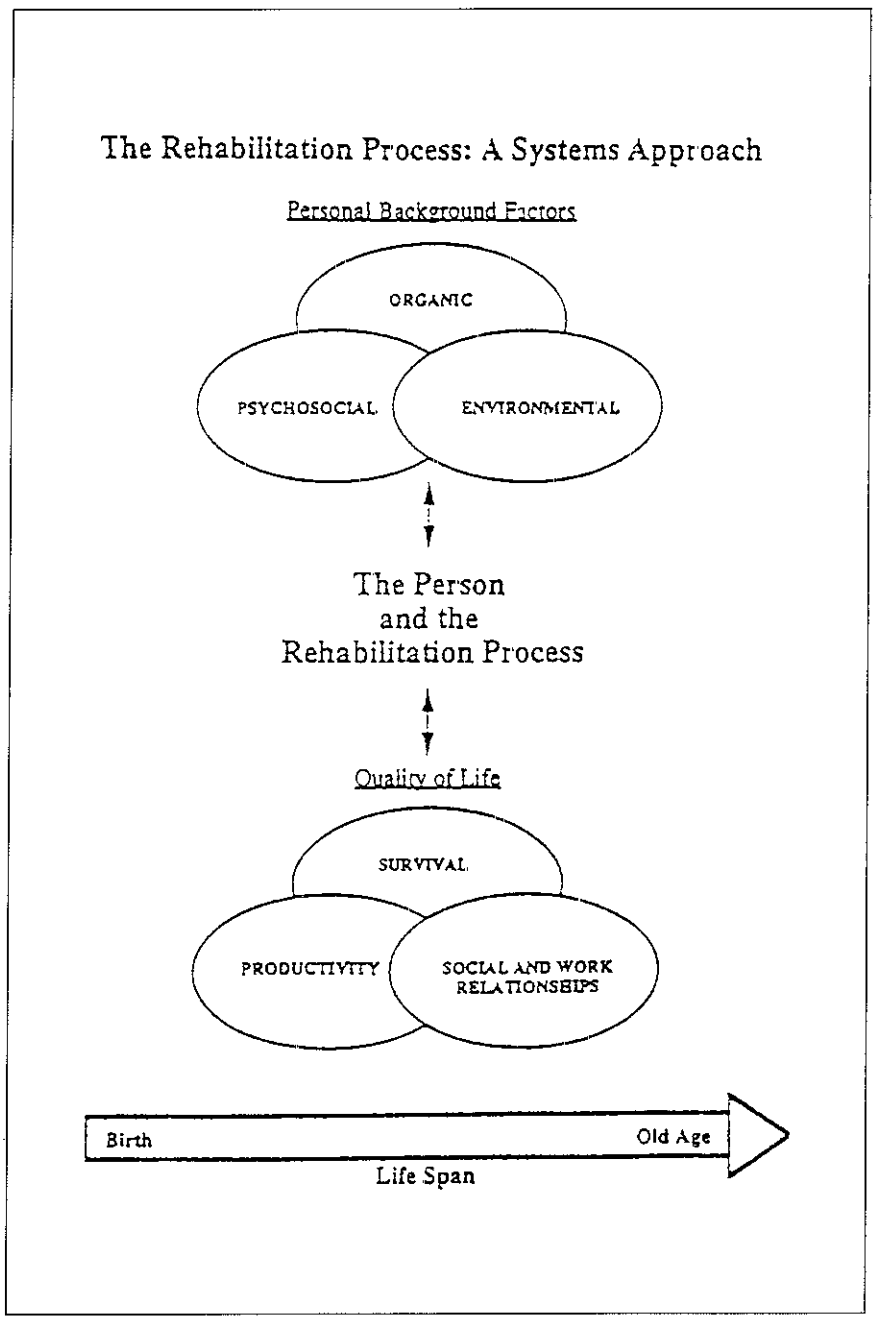


Fig. 1

essence, it can be represented by the following sequence:

Disease or disorder, the intrinsic situation.

Impairment, wherein the experience is exteriorized as the individual becomes aware of the disturbance of health or physical state; it is a biomedical concept of disturbance at an organ leel regardless of its source;

Disability, an objectified functionally oriented concept related to the performance of the activities of daily living as it influences the whole person;

Handicap, wherein the experience is socialized as the individual becomes disadvantaged or devalued to others in society, both local and general

Whereas impairments are heavily dependent on the intervention of primary medical and surgical services, disabilities are the field of rehabilitation involving personnel with a wide variety of specialized training. Handicaps become the province of social policy and welfare services at different private and public levels.

Rehabilitation Process

I am indebted to Dr. Theodore Cole of the University of Michigan and the National Center for Medical Rehabilitation Research (NCMRR) (3), Washington for Figure 1 It gives us the backdrop against wihich the definitions will become more meaningful

The Systems Approach. This newly evolved approach replaces the linear view of the disabllngprocess and the medical rehabilitation process Implied by the WHO concept. The NCMRR recommends that much more debate, discussion, and thought are needed to understand the complexities involved In each individual who is undergoing rehabilitation The two directional arrows In Figure 1 reflect both the complexities and the integration. I agree that the systems approach that NCMRR is advocating is an essential feature of medical rehabilitation, practice and research (and probably also all health care delivery).

Physical Medicine and Rehabilitation. It would be a sad day for us all if physicians backed away from their sacred responsibility—and I use those two words with deep sincerity—to manage or direct the smooth integration of the system. This can be done best by specialists In rehabilitation medicine with grace and wisdom, Instead of awkward interventions in areas where others are better trained and experienced. There will be many good organizational models and, indeed, some are emerging now. Unfortunately, this is not a perfect world, and some workers chafe under the " yoke " of an occasional tactless medical dfrector Believing they are asserting their rights, they will sabotage even the cleverest system. All will lose, especially the disabled persons in their care.

Rehabilitation Medicine. Rehabilitation Medicine (also known as Physical Medicine and Rehabilitation) is a specialty and its practitioners are called physiatrists. Rehabilitation Medicine presents the elements that physicians in Family Medicine and other clinical specialties must clearly understand and appreciate. This should make possible the optimal care that they and all members of the health professions must ensure for the recovery of patient from chronic conditions and from the post-acute stages of acute illness and accidents.

Specific Conditions

Rehabilitation specialists are trained to manage a complex of specific neuromuscular and musculoskeletal conditions that are encompassed in the area of medical rehabilitation. These include spinal cord injury, cerebrovascular disease of various types, cerebral palsy, multiple sclerosis, entrapment neuropathies, muscular dystrophy, polymyositis, the various types of arthritis, soft tissue injury, overuse syndrome, scollosis, peripheral vascular disease, amputations, cardiac diseases, chronic pulmonary diseases, and neurogenic bladder. Related secondary disorders also must be understood and treated, particularly aerobic deconditioning, disuse muscular atrophy, contractures, pressure ulcers, and various types of behavioural and psychological disorders, such as grief reactions and depression The distinctions between impairment resulting from pathology and the consequent disability and handicap are the special province of the rehabilitation physician in the team approach.

Diagnosis and Investigation

The well-trained physiatrist has a practical ability to approach the neuromusclar disorders through their signs and symptoms (e.g. pain, weakness, paresthesias) and understands the various techniques that are available for further investigative studies. This physician should be able to select, requisition, or arrange for the various types of laboratory, electrical or procedural investigations now available, in-

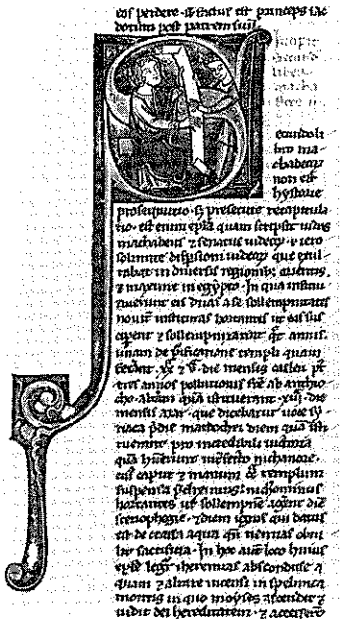
cluding serum calcium, muscle enzymes, myelography, arthrography, arthroscopy, computerized tomography, bone scan, electromyography, nerve conduction studies, stress testing of locomotor or cardiopulmonary function, psychometric tests by psychologists, or the results of urodynamic testing by urologists.

Therapeutic Options

There are a bewildering number of techniques used in medical rehabilitation. Some of them are easy to understand, but some are really more appropriate for non-physician specialists or allied health professionals (e.g. rehabilitation nurses, physical therapists, occupational therapists, social workers, psychologists and others). Given a patient with a neuromuscular or musculoskeletal disorder, the rehabilitation physician is able to select, requisition; or arrange for and monitor the responses to appropriate therapeutic options. These include patient education, special bed care techniques, therapeutic exercise, orthoses and prostheses, functional aids and appliances, therapeutic heat and cold, anti-inflammatory and neuro-active drugs, surgical joint replacement, methods of re-education, milieu therapy, sexual counselling, and behaviour modification. The different considerations include the growing child, the athlete, the pregnant woman, the elderly, and patients with progressive illness. Both care in hospital settings and in the community are also essential considerations

The Rehabilitation Team

While much of what the physician is responsible for will guide future ability to manage patients at home or in a clinical setting, It is still recognized that the rehabilitation team In rehabilitation facilities may be more important that its parts. The formal part of these teams usually includes a physiatrist, rehabilitation nurse, occupational therapist, physical therapist, speech pathologist, orthotist, prosthetist, vocational counselor, social worker, psychologist, with contributions from community agencies and organizations. In the best centers, the most important members of the team are acknowledged to be the patient and the patient's family The role of each member of the team will change from case to case, and at different points in a single patient's transition toward independence. Each profession has been trained to acquire special ability, but each also has limitations. It is the collective team approach, especially the well coordinated team, that has the most to offer.



Summary and Conclusions

This presentation, limited as it is by the brevity of the time allowed, attempts to clarify the essential aspects of the evolving field of medical rehabilitation. It reiterates the author's plea from other platforms for improved terminology, classification and understanding of varying natural histories of individuals.

The *continuum model* of the World Health Organization summarized as *Impairment-Disability-Handicap* was a great forward step, but already is being recognized as too linear. The new National Center for Medical Rehabilitation Research has proposed an alternative rehabilitation process which is a systems approach It recognizes the two-directional, integrated, and complex nature of the process between the " steps " of the linear model. The new approach appears to be an essential feature of medical rehabilitation practice and research.

Physical Medicine and Rehabilitation (PM&R), or just Rehabilitation Medicine. Is the field of health care that involves a wide array of specialists, who may or may not act as a team for individual patients. They include the physiatrist (i.e. the physician specialist in PM&R), rehabilitation nurse, occupational therapist, physical therapist (physiotherapist), speech pathologist, orthotist/prosthetist, vocational counselor, social worker, psychologist and representatives of community agencies and organizations.

The medical specialists in PM&R have a special role and responsibility over and above membership in the rehabilitation team: to coordinate the efforts, especially as they interface with outside agencies. Although in some countries physical therapists are agitating for autonomous direct access to patients without physician involvement (much like chiropracters), in medical centers the integrated approach is the norm, and likely will remain so.

Today's physiatrists are a far cry from the pioneers of the 1950's. Now, they have undergone intensive and extensive training in the diagnosis and management of the post-acute and chronic states of neuromuscular and musculoskeletal conditions, including spinal cord injury, cerebrovascular diseases of various types, cerebral palsy, multiple sclerosis, entrapment neuropathics, muscular dystrophy, polymyositis, arthritis, soft tissue injuries, overuse syndromes, scoliosis, peripheral vascular disease, amputations, chronic pulmonary diseases, and neurogenic bladders —not to mention the host of complications all these lead to.

With the special training implied by the above, the rehabilitation physician is called upon to select with the patient's help from the bewildering array of therapeutic options and to call upon specialized therapists and technologists both for improved diagnosis and specialized treatment regimens. In rehabilitation centers, the team approach is widely used.

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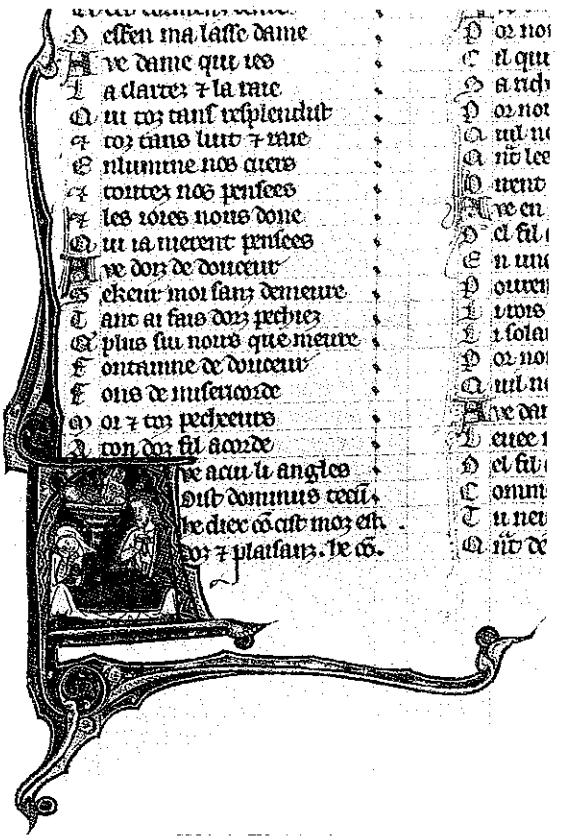

MARIANO GALVE

Psychology and Rehabilitation

I am very grateful to the Pontifical Council for Pastoral Assistance to Health Care Workers for this opportunity granted me to speak in this place and pay testimony to a truth borne out by humanity and attention: the importance of emotional and psychological questions in all kinds of rehabilitation. This aspect, in my opinion, is often put into the shade and not taken into consideration because it comes into conflict with the power of medicine and its technology which is nearly always directed towards the physical aspects of rehabilitation. However, and this is my first belief, any project of rehabilitation can not reach its objective if it fails to make the afflicted person a dynamic force. This supposes a journey through the vortex—which is not necessarily catastrophic—of his impulses, emotions, frustrations, and successes. That is to say, if it does not pass through his individual and practical psychology. Furthermore, I also believe that when this is done those who are involved with him—whether doctors, those dealing with his rehabilitation, his family, or society—enter into a dimension of humility which embraces and involves them but which, in the long run, helps them to build themselves into the noble work of enabling the handicapped themselves to live out their lives.

I often have the impression that on the great stage of life the person afflicted by disability is attributed a minor part and that too often he is a silent bystander who must see, feel and decide as others see, feel and decide for him. For this reason, my paper will deal with each of these subjects—the family, doctors, professional workers, and society as a whole. I will define what they are, point out the traps they fall into, and demonstrate their limits.

I am convinced that such a subject should be dealt with by a handicapped person. Nevertheless, I will venture to talk about such a person with the conviction that I also am disabled. Whatever the case, I apologize if I offend anyone or do not understand them well.

General Aspects

1. *History*

Handicapped people do not now make up a forgotten group. The elderly and the majority of those born before 1940 lived without the help that is available now and the seriousness of the handicap that they now suffer from is the result of that previous neglect.

2. *The Objective*

Nowadays, the concepts diffused by the holistic health movement and ecological health models emphasize the importance of treating people as biopsychosocial beings. There is ever-growing evidence to the effect that treating someone in his entirety is not only a humanitarian act. Integral emotional and physical care and treatment can bring about positive results with regard to disability.

3. *The Process*

The individual with a handicap must face up to a complicated number of specialist treatments carried out by doctors, nurses, professionals, and non-professionals such as the family and the environment. But in this scheme of things psychology should not be forgotten. This is because the rehabilitation of every disability can not be achieved without reference to the mind. Just as any kind of physical threat is accompanied by physical stress, so the survival of the emotions is also a vital question when a disability has been acquired.

4 *The Symptoms*

The process and the content of the emotional aspects of rehabilitation are bound up with the physical recovery of the handicapped person. Emotional rehabilitation is as necessary as medical rehabilitation. The patient's response to such phases as shock, rejection, depressive reaction, reaction against independence and adaptation will have a major role in facilitating or hindering the success and unfolding of the rehabilitation.

1. The Handicapped Person Himself

The loss of control of the essential functions of the body or the mind is an experience which is terribly traumatic. The individual comes to consider his body, or a part of himself, as an " alien object which is in no way his own. " The meaning of this state of inadequacy includes the fearful knowledge that the organs of the body—and in certain cases also the mind—have ceased to be valuable and obedient instruments which carry out the orders of their owner. How can we acquire a complete picture of these feelings? One thinks of the feelings of inadequacy and of the labels

which accompany the descriptions often used in referring to handicapped patients. Insignificance, uselessness, impotence, unhealthiness, abnormality—these, and many others, are the words which can help us to grasp what it is that the handicapped or disabled person really experiences and undergoes in his life.

1.1. *The Self*

The incapacitated person considers himself within the light of a number of different labels: mutilated, spastic, paralytic, amputated, different. This feeling of being different can become stronger, at times, and give way to an unbearable feeling of being segregated and to an oppressive anxiety about the future which leads him to believe that constructive answers are necessary to regain confidence in himself.

The handicapped people who are already vulnerable because of their narcissism feel that they are useless and despicable as a result of their disability. The perception of their " self " as being abandoned and out of control can lead them to have a much lower view of themselves. Hope, which is usually unconscious at times of personal powerfulness, can give way to anxiety created by vulnerability. Contempt and disregard on the part of other people, who are considered as critics, are feared. In this mental state, the " self " is seen as a mere concept and feelings of shame are born.

1.2. *The Social Self*

Incapacity is a principal source of stigma and tends to contaminate the social identity of the individual and his social relationships. The stigmatized individual is someone " who could be received with ease into a normal social relationship " (but) " has something that hinders that relationship and distances anybody who comes near to him and obscures in the eyes of other people those attributes of his which could be considered unattractive. " Furthermore, the stigma acts to make his other defects even more noticeable. The characteristic features of stigma resulting from incapacity change according to the personality of the handicapped person himself, the kinds of people that the handicapped person comes into contact with, and the naturalness or otherwise of the social context that he moves in. They change, at the same time, according to the definitions and projections that handicapped people have in regard to themselves. I am referring here to such perspectives as evaluation or contempt.

1.3. *Emotional Consequences of Incapacity*

The syndromes of response to incapacity are characterized by episodes of ideas, thoughts, and forms of behavior that the subject does not control. The same may be said for periods of negation of ideas, emotional weakness, restricted forms of behavior.

Amongst the most important mental states that the handicapped person experiences there stand out an overwhelming sadness, fear, anger, and a sense of blame and shame. There is a predisposition to each of these reactions according to the individual's internal balance of certain images of his own " self " and certain images of other people.

1.4 *Two Alternatives: To Succumb or to Fight Back*

The succumb approach is characterized by feelings of difficulty and discouragement when faced with the reality of being incapacitated in contrast to an attempt to change attitude in response to a challenge which gives new meaning to the condition of being handicapped. There is an insistence upon what the person can not do; upon what is denied to him; and upon the problems that depress him. The most important thing is the handicap. It is something which has an impact on all the aspects of the life of a person. The individual within, as a separate and unique personality, becomes lost when confronted with these sad realities.

In place of a framework by which the person is measured by facts there arises a constructive point of view towards the incapacity. This basic attitude orientates the person who undergoes this incapacity to see and appreciate himself as the possessor of a capacity which has an intrinsic value. Those afflicted by disability consider themselves as active participants in their own lives and those of the community around them and not as passive victims of destiny and people destroyed by a whole host of problems and difficulties.

1.5. *The Handicapped in Relation to Their Own Rehabilitation*

The convulsive alterations caused by the tensions involved in adapting to his incapacity require a reintegration of the emotional and perceptual capacities of the person. The psychic mechanisms which are used must be examined with the aim of reinforcing them where this is possible. Other alternative mechanisms must also be studied. In the same way, steps must be taken to form and shape what is necessary to the corporeal image of the handicapped person. These new psychic and physical frontiers must reflect a new and emotionally integrating sensation of the fullness of the body and of the " self. "

For this reason, each subject must attain a certain level of tolerance towards his own changed body or mind so as to integrate the emotional, physical and cognitive selves. At the same time, he must wait for other people—those who are dear to him and share his life —to respond in the same way. The process of struggle begins to have a positive outcome when the person is able to recognize the limitations imposed upon him by his incapacity and which can lead to his dependence upon other people. It is necessary to separate this physical dependence from a feeling of loss of worth as a human being.

At the outset, the process of rejection which operates underneath the consciousness often protects them from the additional pain which derive from an observation of the threat produced in the sphere of the " self. " For this reason, in order not to accept all the implications of his deficit his struggle will go on until the resultant incapacity can be incorporated into the sense of his own individuality and until it is possible to recover his self-esteem even though his body or his mind is incapacitated.

The same happens with regard to damage to integrity whatever its

cause may be. The handicapped person not only has to adapt to his limitations—he must also take into consideration the exclusive meaning that the handicap has for him at every moment of his life.

The struggle to go on living with reduced functional capacities will accompany the person for all his existence whatever the level of recovery of his functional independence or his " self. "

One is dealing here with the fact that the individual can achieve a new positive compromise with his own life and define anew his " person-being. " He can do this armed with a vision of himself as a valid and valuable member of the society which he finds around him.

2. The Family

Although the incapacity directly affects one person in particular, its impact of the deficit is regularly felt by the whole system of familial interrelationships. This process of impact and adaptation requires a deeply probing calculation which uses means which are up to the job of ensuring a system of constructive support.

Both the alterations which are produced in the short run and those which are permanent must be assessed and thought about. This must be done in a way which displays flexibility and is devoid of prejudices.

2.1 *The " Impact Process "*

Every form of handicap presupposes a hard blow for every kind of family system. This is so for a variety of reasons:

2.1.1 The first touches upon its innermost and deepest reality— its narcissism. Both in the case of the loss of a perfect child and when one is born with congenital problems, the parents suffer a profound wound in their " narcissistic self. " Their sense of guilt are great and constantly direct their attention to what should have been done—something obviously different from what they actually did—to stop the deficit. Their sadness is frequently mixed with anger felt towards their partner.

2.1.2. The second reason consists of a frightened discovery of their responsibilities. The individual's perception of himself is particularly subjective. But in the case of children or of that of many handicapped people it is also true that they come to see themselves in relation to how their parents see them. Furthermore, handicapped children and those who are very vulnerable do not feel their defect as such—they see it as something which is " normal. " This is because it is the only reality that they know. With regard to any aspect which their parents do not recognize and to which they do not respond such as anger, the desire for independence or a physical or psychic defect, there can be no guarantee that such does acquire a psychological existence for them. In addition, they cannot be integrated into their self-image and range of responses. The children depend upon the reflexive emphatic responses of their parents in order to develop a coherent sense of themselves.

This means that there is an additional burden on the parents who find that they must control and be responsible for the behavior of their child in so much as it is a reflection of their relationship with

him and of his parenteral capacity. The majority of parents feel themselves oppressed by feelings of guilt because they are not able to do their protective duty and ask themselves at a profound level if they possess enough abilities to deal with the situation.

2.1.3. The third reason involves a threat to its balance. Loss of control and panic are commonly observed in families. Their defensive groups of responses are full of anxiety when faced with an excessive coming and going or the turmoil of an anxious situation.

2.1.4. Finally, there are a whole variety of practical problems which build up. Amongst these there is economic loss, transport difficulties, and responsibilities involved in looking after the child. Because of an increase in expenses at a time at which income can fall, financial tensions can limit the ability to solve other problems. The resources that the community can offer to tackle immediate needs are inadequate and difficult to obtain. On the other hand, that which is required of families to receive this social help constitutes a further loss of personal dignity and patience.

Narcissistic injury, responsibility, threat to balance, and the thousands of small anxieties of daily life, have a profound effect on the relationship of the handicapped person with his family. The response of the family to a deformity or incapacity is often, for the person who is afflicted, a special phenomenon in attitudinal terms. This special feature often consists of considering the young person as something which is delicate, fragile, and in need of excessive protection. As a result, they inculcate a double feeling of inadequacy and ineptitude and, at the same time, the feeling of having a right to everything there is.

2.2. *The " Adaptation Process "*

In general, the family goes through a process of adaptation which is divided into five separate phases: 1) shock; 2) negation; 3) sadness and anger; 4) balance; and 5) reorganization.

The process of learning to live with a handicap begins at the moment when the incapacity is

born. It continues for the whole of life. The dynamics of the family touch upon this process. Interrelationships between the handicapped person and the family members which stimulate participation, hope, and independence in a caring and encouraging environment can mobilize the forces which act for rehabilitation and adaptation in relation to the handicap.

However, very often, a handicapped person and his family need individualized and complete treatments which respond both to their physical and to their emotional needs. An increase in the physical possibilities of a person becomes useless if psychosocial incapacity impedes its adequate use.

But the real possibilities of doing so are another matter. This is because the intense consultation needed to solve these feelings is not usually available in the rehabilitation centers. Or there is no benefactor to help the family. Both circumstances can also apply.

3. Society

3.1. Amongst the needs felt by people in their relationships with others there are present affiliation, affection, and emotional attachment. An important dimension consists of the extent to which the needs and capacities of people match their opportunities to express themselves. In this way, for example, many handicapped individuals relate how other people avoid them. This suggests that there is an absence of adaptation in these interpersonal relationships and further suggests that the environment does not contain enough resources of support and affiliation.

3.2. But the presence of conditions which are in no way encouraging suggest that the nonhandicapped avoid relations with the handicapped because of the anxiety, the concern, the unreasonable fears, and the emotional discomfort that healthy people feel. In this way those who do not suffer from an incapacity contribute to the stigmatizing and isolation of those who do. This distancing and defensive attitude hinders the development of behavior suited to the modification of social relationships engaged in with handicapped people.

3.3. Furthermore, when families come up against a crisis in their lives (the incapacity of one of their members for example) they often experience a very keenly-felt need for social support, attention and affection precisely at the moment when there are less chances of receiving them.

Given that their normal activities are reduced because they have to deal with the crisis which has befallen them, normal social contacts decrease at the same time as there is a decline in situations which previously produced a sense of belonging, love, and appreciation.

It must be recognized that a kind of barrier to integration exists which to a certain extent all severely handicapped people suffer from. And while the attempts to reduce these barriers continue (for example, through study or early teaching) we must, in our present situation, accept as a goal the partial integration for certain severely handicapped people. Perhaps the yardstick of good judgement and the maturity of a community is furnished by the extent to which their members know how to adapt to the very great differences between certain groups—as regards color differences, political ideas, intelligence or the contrary—and to maintain a total feeling of unity and mutual respect. A pluralistic society does not expect all its members to respond in the same way. The achievement of integration is, to a certain extent, what is ideal, and if the community accepts it, even if not totally, both handicapped and healthy people will enjoy a life which is much fuller and much more rewarding.

4. Professional Workers

4.1. In the professional areas which work for rehabilitation major attention in treatment must be concentrated almost exclusively upon an ending or a reduction of the effects of the physical deficit. When to this is added the list of needs that the handicapped has in relation to psychological or emotional rehabilitation, the enormous number of services becomes a heavy burden which it is not possible to bear. At that point the professionals, with the approval of the administrative authorities, concentrate upon those methods which seem to display most effectiveness and return: matters relating to physical needs.

4.2. Furthermore, there is a tendency to bestow the professionals with faith in their ability to know what is best for other people. In doing this they employ a language which distinguishes them from the ordinary general public. There is also faith in their technical resources which enable them to distinguish themselves from the recipients of their help. The importance of these attitudes lies in their ability to effect a treatment rather than an educational model of rehabilitation—something which justifies the practice of working " on " rather than " with " handicapped people.

4.3. A professional must consider a more humanistic psychosocial perspective which is focused upon elements like the quality of life and the special meaning that a handicap can have for a certain person. This will lead him to have considerable satisfaction and take important steps ahead in achiev-

ing an authentic system of complete treatment.

4.4. Help is not a simple phenomenon of common sense rooted in the good intentions of the person who helps. It is, rather, a complex interpersonal relationship that can have a whole host of meanings. If the help given by others is to increase to the utmost and if there is to be relief given to the frequent frustrations that arise between those who give and those who receive, then many different aspects of the whole question must be understood. The function of help and the idea of rehabilitation is nothing else than enabling the person who suffers from incapacity to act anew to achieve the goals that he himself sets and, furthermore, to carry them out in an effective fashion.

We can characterize the three classes of help in the following ways:

4.4.1. " Let me do that for you. " In this case, the aim of rehabilitation is the relief of suffering

4.4.2. " I will help you but insist on the fact that you learn to take care of yourself. " The aim of rehabilitation is independence.

4.4.3. " I will help your choices and your opportunities to grow. " The goal is the freedom to struggle to achieve objectives which are important for the individual. Naturally enough, this should take place with due respect for the needs and the goals of other people.

4.5. The personnel involved in rehabilitation also interact with the families of the patients. However, they do not always recognize the family members are also destabilized and also go through a rehabilitational process. The family and the systems of treatment, indeed, choose different positions in relation to the patient. A triangle is formed in which the sick person finds himself in the middle and his relatives and the professionals complain that the family interferes in the treatment. The family thinks that the professionals do not help the patient enough. They blame each other in an attempt to express and distance their own frustration rather than direct it towards the patient, who is vulnerable.

5. Programs and Methods

5.1. From an ecological perspective it is clear that a handicapped person needs the following " environmental inputs " to face up to his handicap with success:

5.1.1. Opportunities to take action and make decisions.

5.1.2. Behavior on the part of personnel taking care of the handicapped person which indemnifies him against the attempts he makes to overcome his situation and which upholds his sense of dignity.

5.1.3. Policies and organizational procedures which respect his forms of life, his cultural values, and his aptitudes.

5.2. Rehabilitation is a " process of behavioral change which aims at teaching a person to live with his handicap in his own environment. "

In the traditional model a group of experts carries out its work " on " the patient so as to put his body in order. In an educational model the professional works " with " a handicapped person and, at least theoretically, with his family as well, so as to teach them new possibilities and forms of behavior. In this educational model,the handicapped subject must be an active participant in the whole process

In order to correct the weakness of the usual method of rehabilitation, certain different things are required:

5.2.1. The first would be individualized programs forged out of a contract between the handicapped person, the agent responsible for the treatment, and the insurance company. This system implies an identification of the goals which have a meaning for the patient, even though this may not always be true for the professional personnel.

5.2.2. The second is a modification of the physical environment so as to encourage the independence of the handicapped person using the method of a simulation of the family situation.

5.2.3. The third would be that of giving the patients the opportunity to deal with each day in an integral, rather than a fragmented, fashion.

5.2.4. A fourth requirement would consist of ensuring that the people who help the patient should be seen as teachers and not as " curers "; perceived as cooperators not as " saviours. "

6. Conclusion

6.1 Whatever the handicap may be, the return of the psyche and the body have a crucial importance for life as a whole. Although history can not be changed, each patient finds himself in the position of freeing himself from the clutches of a history of an incapacity to reach, on his own, an attainment of his full potential.

6.2. In this challenge all of us are important: family, environment, professionals, and society itself. But the most important role of all is that played by the handicapped themselves. If we all push in the same direction we will make our world a little more liveable.

As Arnold Toynbee said: " The essential thing in human life is the presence of challenges to which we can reply. " In our field, the challenge is clear.

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Psychological Value of Sports Activities for Disabled Persons in China

I. Introduction

The development of sports activities among disabled persons has important psychological effects on both the disabled themselves and the people of all social walks. It inspires the disabled to realize that they may enjoy, to the extent of their full potential, the same civic rights as the able-bodied to participate in normal social life, and may earn the same respect from society. The courageous spirit of disabled athletes and their brilliant achievement give very much positive psychological stimulus to all the disabled to overcome their psychological barriers in their social activities, such as inferiority, low self-confidence, and underestimation of their potential. The distinguished achievements of disabled athletes indicate eloquently that the morale of the disabled is not broken though some of their physical functions are disabled. They are still productive creators not only in material civilization but also in spiritual civilization for the whole community. Their sports achievements and their spirit in competitive games also change social stigmas of the disabled. So sports activities for the disabled not only build up their physical strength, but make many contributions to the development of healthy psychological values as well.

1. *The prevalence rate of the disabled in China.* As a developing country with the largest population in the world, China is facing a substantial number of disabled people to be served. In 1987, a nation-

Table 1. Chinese disabled athletes in domestic and international games

	time	athletes	achievements
Domestic			
1st National Disabled Games	1984,10	574	4 events and 1 performance.
2nd National Disabled Games	1987,8	907	4 events, broke 197 national and 9 world records
3rd National Disabled Games	1992,3	1153	4 events, broke 103 national and 28 world records
International			
3rd Far East and South Pacific Disabled Games	1982,10	15*	3 events, 6 gold, 12 silver and 7 bronze medals
7th Para-Olympics	1984,6	24	3 events, 2 gold, 13 silverand 9 bronze medals, broke 9 world records
4th Far East and South Pacific Disabled Games	1986,8	23	3 events, 66 gold, 21 silver and 3 bronze medals
8th Para-Olympics	1988,10	43	3 events, 17 gold, 17 silver and 10 bronze medals, broke 10 world records
5th Far East and South Pacific Disabled Games	1989,9	56	3 events, 99 gold, 34 silver and 10 bronze medals, broke 15 world records
9th Para-Olympics	1992,8	24	5 events, 11 gold, 7 silver and 7 bronze medals, broke 11 world records

* including athletes and working staff

wide sample survey with a standardized criteria to identify five kinds of disabled, including those with vision, hearing and language, intelligence, physical and mental impairment, was carried out among 1,579,314 people from 369,816 families from 424 counties of 29 provinces, municipalities, and autonomous regions of the Chinese mainland in 1987, with a prevalence rate of five kinds of disabled at 4.9% in the total sampled population. Based on this sample survey, it is estimated that in the mainland of China there are about 51 million disabled people. Families with such persons make up 18.1 percent of the nation's total. This indicates the importance of solving the problem of the disabled and the families involved in China.

In recent decades, the Chinese government has paid much attention to the well-being and interests of the disabled and provided them special assistance and protection in order to reduce or eliminate the effects of disability and the external obstacles, improve their social life, and get jobs in the community

2. *Protective laws and organizations for the disabled in China.* China's constitution provides the guarantee for the disabled to enjoy the same civic rights as the able-bodied. The Law for " The Protection of Disabled Persons " was adopted by The Standing Committee of the National People's Congress in December 1990. This Law, the first of its kind in China, guided by the principles of " equality, " " participation, " and " co-enjoyment, " stipulates that the disabled enjoy equal rights with other citizens and are protected from their infringement. It also states that measures of support and help shall be taken to develop undertakings for the handicapped, promote their equal participation in social life, and guarantee their share of the material and cultural achievements of society. The official announcement of the Law is, in fact, the most important step of China to respond to the UN World Action Program Concerning the Disabled.

Many important laws such as the General Principles of the Civil Law, the Civil Procedure Law, the Marriage Law, the Inheritance Law, the Electoral Law, and the Compulsory Education Law have special provisions guaranteeing the rights and interests of the disabled. The China Five-Year Work Program for Disabled Persons (1988-1992), developed jointly by various government departments concerned, has played an active role in promoting the government's effort in recent years.

In March 1984, with approval of the Chinese government, the China Disabled Person's Federation (previously the China Welfare Fund for the Handicapped) was established. The federation represents the common interests of all the disabled, protects their lawful rights and interests, and mobilizes social forces to serve them. Its local branches were developed on the basis of national administrative divisions. Federations of the disabled have seen set up in all provinces, municipalities, and counties.

Also China has set May 19 of each year as the legal National Day for Helping the Handicapped.

3. *Achievements in protection for the disabled persons.* The Chinese government and social organizations have made great efforts in ensuring rehabilitation, education, employment, culture, physical training, welfare, and a better environment for the disabled. Only in the four years, for example, more than 700,000 cataract patients have undergone operations to recover their vision; some 250,000 people have undergone corrective surgery for sequelse of poliomyelitis, and more than 20,000 deaf-mute children have received language training. In addition, 204 special education schools were created annually, while the special education classes in general primary schools were doubled each year, and the number of blind, deaf-mute, and mentally retarded students in school increased annually by 30%.

Thanks to the efforts of public and government, the number of welfare enterprises established by government departments at all levels to provide job opportunities for disabled people who work in general enterprises account for 1% of the total number of employees on the average. All these make up an

employment rate of more than 60% for both rural and urban disabled people in some areas.

II. Sports Activities for the Disabled in China

Disability one is usually not only in physical dysfunction but also in behavior and psychological impairments, social withdrawal, loss of self-confidence, and underestimating one's full potential. Based on the requirement put forward by WHO in the health definition of " physical, mental, and social well-being, " it is important to improve the behavior and psychological status of the disabled while a physical replenishment is offered.

Physical culture for the disabled is an important way for them to take part in social life, and in turn, their self-reliance and, fighting spirit is also a strong inspiration to all of us.

The government's cultural and sports departments at all levels actively organize and support cultural, sports, and recreational activities of the disabled, enriching their life and guaranteeing their equal cultural rights. Today there are in China 1770 cultural and sports centers for the disabled to carry out activities such as calligraphy, painting, photography, stamp collecting, track and field, ball games, chess, and art exhibits. The China Sports Association for the Disabled, established in 1983, has joined with world handicapped sports organizations. The government now allocates special funds to sports activities for the disabled each year.

With strong support from public and government, handicapped people in China have participated more extensively in domestic and international competitions and exchanges, and their efforts have received much praise.

In recent years, China has held three national sports meets for disabled athletes and participated in the Para-Olympic Games and disabled sports competitions of the Far East and South Pacific Region three times, winning nearly 200 gold medals in world competitions (See table 1).

Furthermore, the government has decided to host the 1994 Disabled Sports Meet of the Far East and South Pacific Region and expressed its wish to hold the Para-Olympic Games in Beijing, too.

Two of the Most Recent Examples

1. Domestically, the Third National Games of the Disabled, the largest-scale disabled games in China, were held in Guangzhou from March 18 to 23, 1992. Based on the principles of equality, participation, self-reliance, and courageous effort, 1200 handicapped athletes from all over the country and the Hong Kong and Macao regions displayed many brilliant achievements in these Games. Twenty disabled athletes broke 27 world records for 42 times; 136 persons broke 103 national records for 238 times through unflinching courage. They showed clearly the spirit of self-respect, self-confidence, self-reliance, and self-support. It improved sports levels of the disabled and indicated the rapid development of the cause of the Chinese disabled.

A total of 800,000 people watched the third national games for disabled. They not only enjoyed the games, but wanted to discover a kind of pure spirit, which was presented most clearly in the " Appolo-Song of Life ": " Forging ahead into the future, though disabled. Challenging destiny, fighting against nature, Stirring, leaping, combating. The tuning of time and fate has come into being. "

This shows that the disabled persons are breaking through their isolation to seek understanding. They are coming out of their narrow circle to the open society. They are casting off their solitude and beginning to seek contact with others. Physical exercise builds up their strength. Moreover, it augments their confidence and overcomes their psychological barriers. They return to society and become creators of both material and ethical culture.

2. Internationally, the 24 Chinese athletes who took part in the

Ninth Para-Olympics in Barcelona brought home 11 golds, seven silvers, and seven bronzes for five events. The number of gold medals won by Chinese athletes paralleled that of Denmark and South Korea, and China placed 11th in the number of gold medals won and 18th overall. Eight Chinese athletes broke world records 14 times, and 11 broke Para-Olympics records 21 times. They won great honor for their motherland in the international matches.

III. Conclusion

The progress of Chinese disabled athletes displayed at the meet was spectacular, especially considering how late the disabled sports movement started in the country and the limited facilities compared to those of developed countries.

In recent years, the cause of the disabled in China has made great progress, and the disabled sports movement have also gained further development. Through sports training and physical recovery, the disabled strengthen their ability to take part in social activities. Their spirit of self-reliance constantly encourages people, and the disabled make an important contribution to the development of material and spiritual civilization.

The recent successes of the disabled sports movement in China indicate eloquently that the disabled person can have a solid material foundation only after reform, openness, and economic development. Reform and openness not only bring about economic prosperity, but also encourage disabled people to take part in all social activities on an equal footing with normal people. They improve the mutual understanding between handicapped people and society, the establishment of spiritual civilization, and enhancing of socialist humanitarianism.

I would like to pick up the words from a popular song sung at the Third Chinese National Games of the Disabled to end my presentation. It states: " If everyone devotes some love, the world will be full of happiness and peace. "

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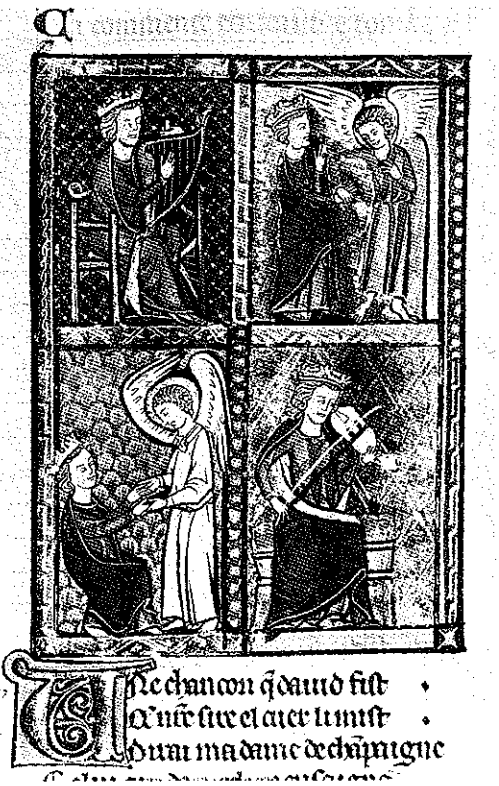

ARTUR A. ASKALONOV

The Social Integration of Invalids

At the present time, according to the data provided by international organizations, the percentage of handicapped people in the population structure is on average about 10%. In some countries, such as Canada, Finland, Poland and the United States of America, this percentage is between one and a half and twice as high. In the Russian Federation they amount to about 4.3 million people. In addition to these, within the category of the chronically ill suffering from very serious ailments, about thirty-five million people, according to objective criteria, may be defined as being handicapped. Amongst the invalids, the largest group (about 20%) is made up of people with illnesses of the internal organs and about 15% are mentally retarded who suffer from innate or inherited illnesses and have developmental anomalies. About the same number is made up of invalids who have psychic dysfunctions, are alcoholics, or are drug addicts. The costs of this situation are enormous. The direct payments alone caused by the temporary loss of work capacity amount to forty milliard rubles. Even more striking is the cost of treating and taking care of the chronically ill, not to speak of the contribution to the economy lost by this evident reality. The total sum amounts to sixty milliard rubles each year.

It can be seen, therefore, that the problem of invalidism is a universal phenomenon. Its solution is an international task and involves all the countries on the face of the earth.

The objective need to achieve the perfecting of medical and social care for invalids is based upon, and

borne out by, a change in the most important sociohygienic and socioeconomic criteria for public health. For example, over the last twenty years the number of invalids has increased by 10% notwithstanding the measures which have been adopted. The most gravely afflicted invalids (the first and second categories on our scale) have increased by 10%. The number of invalids who have regained their capacity to work in full or at least in part has decreased by 50%. The number of invalids involved in productive work has fallen by 33%.

As a result of increased competition in the labor market, a further worsening of the situation and a heavy deterioration of the economic condition of invalids are envisaged. At the present time, social policy towards these invalids is based upon compensations—that is to say, upon financial contributions from the state in the form of pensions and payments. This policy ignores the productive capacities, real opportunities, and needs of the invalids and fails to orientate society and the invalids themselves towards a development of the potential of their individual personalities. Furthermore, this policy is unable to guarantee the creation of conditions which favor their integration into society.

The consequences of this policy are such that at the present time there are no reliable data on invalids, not to speak of facts and information on their needs and the kinds of social-medical help and assistance that they require.

At the present time, a certain medico-social system for the rehabilitation of invalids aimed at reintegrating them into society has been

brought into being This process involves establishing the state of their health, suggesting the professional direction they might take, organizing professional training, the finding of jobs, and helping the invalids to adapt themselves to society and to daily life.

In order to obtain the required efficiency and effectiveness in the co-ordination of these attempts it is necessary to perfect and modify the existing system which should be all-embracing, have a multifaceted and multi-stage character, and take into account all the social and professional dimensions involved. In line with the needs of the invalids the following number of rehabilitational measures should be adopted:

1) exploit the possibilities offered by the work, educational, and health systems;

2) create a network of recovery centers specializing in the medical, social, and professional rehabilitation of invalids who are afflicted by the serious consequences of traumas or illnesses.

To this end the various regions in Russia have created recovery centers for the different categories of invalids and in particular for war veterans and invalids from childhood who have neurological and psychic dysfunctions, sight and hearing impediments, or spinal traumas.

The most effective operational centers are:

the center for medical rehabilitation and physical methods of treatment at Moscow;

the Dikul Center at Moscow;

the center for the recovery of spinal victims organized in conjunction with the hospital clinics (nos. 6 and 19) at Moscow;

the centre for the rehabilitation of children afflicted by cerebral paralysis at Moscow;

the Rus (Moscow region), Baikal (Irkutsk), Kuban (Anapa) and other centers for medical rehabilitation for war victims and the members of their families.

At the same time, only 20% of the applications for rehabilitation meet with a positive reply.

At the present time especial difficulties are evident in the field of orthopedic care. We still do not have precise data on the invalids who have need of help in this area. In 1990-1991 the Energhiya association, in conjunction with institutions dedicated to orthopedics and with industrial bodies responsible to the Ministry of Social Services for the production of protheses, carried out a survey of invalids on the books of the various orthopedic centers and institutes. According to the results of this survey, about 360,000 people need protheses whilst the total number of invalids who belong to this category in Russia who have made (or have not made) applications for orthopedic assistance is in the range of 700,000. The total number of orthopedic companies, whether small or large, factories, or laboratories, in Russia is 66. In Western Germany alone there are 600.

The engineers and technicians who work in this field number 300 and they help 200,000 people each year. On average each worker produces 20-30 protheses each month. In the West his colleague manufactures 5-6. The low technological level, the lack of necessary materials, and of required machinery, hinder the making of protheses which come up to modern standards of quality, durability, and design. All this renders the invalid's social integration difficult.

We now also have the problem of social care for ex-military people who have been victims of mutilations and contusions in recent conflicts in other countries. In total they number about 36,000. 6,800 of them have become invalids—the more serious number 1,150; the less serious 2,300; 3,300 have light mutilations. About 900 people have lost legs. 202,500 are afflicted by serious illnesses. About 80% of them are thirty or under. Foreign countries provide a certain amount of orthopedic help for this category of patients. For example, 350 people are treated abroad. Of these, 40 are in Italy, 50 in Yugoslavia, 94 in Germany, 125 in Cuba, and 15 in Israel.

The state is seeking to provide structural, legal, and socioeconomic assistance so as to guarantee the rights of its invalid citizens. A person who becomes an invalid must be fully integrated into society; he must have the opportunity

to create or keep his nuclear family; he must be able to find a job. Society, for its part, has the duty in relation to these invalids to ensure that barriers to their full integration into normal life are removed. The invalids must be guaranteed a place to live, medical care, and social security. They must have the opportunity of receiving an adequate education and of having normal access to cultural and sporting life and to public transport. The needs of invalids must be taken into account at a legislative level as well when social and urban programs are discussed. Such programs can not be adopted without the needs of invalids being taken into consideration.

Much must be done with regard to adapting the public transport system to these needs. There is also a great need for the development of the production of personal means of transport for these invalids. I am thinking here of various kinds of wheelchairs which are presently very much missed and in much demand.

The development of home care for invalids is of primary importance. It can help them to have stable contacts with the outside world.

898 pension-homes exist in Russia and in these homes there live more than 260,000 elderly people and invalid children. The state must guarantee them an adequate standard of life, medical care, special programs of rehabilitation, and the chance to engage in certain kinds of work.

Within the framework of humanitarian aid, our partners Great Britain, France, Germany, and the United States of America are creating a number of pension-homes for invalids in various regions of Russia. In this way from September 1992 the Cescira Home (GB) in Moscow for military invalids will be in operation. Its members will be able to take advantage of professional and social-medical programs of rehabilitation. The construction in Russia of a number of special institutions (including specialist hospitals) to provide social-medical care for sick and invalid people is envisaged. At the same time it will be necessary to also create similar low cost structures for elderly people and invalids.

The state, for its part, must give invalids special tax concessions, cheap public transport rates, help with payments for common expenses in apartment blocks, and supply contributions towards the price of medicines and so forth.

The state program for the training of specialized medical and paramedical staff, psychologists, and so forth is of great importance. The experience that other countries have in this field could be of great help to us.

Russia believes that international cooperation in this field is essential and further believes that it is necessary to take part in existing international programs and, in time, to be a signatory to existing agreements connected with the United Nations, the International Labor Organization, the International Association for Social Security, and other similar bodies. We believe that it is necessary to take steps to ensure real co-operation between those bodies which are responsible for the condition and welfare of invalids, institutions, and social organizations, and the countries which are most advanced in this field. The approval by Russia of the law on the guiding principles of social care for invalids will favor the creation of " joint-ventures " dedicated to the production of equipment for invalids, not to speak of commercial activity of governmental, social, and cooperative enterprises on behalf of invalids and with their participation. We hope to expand, from this year onwards, practical cooperation with the International Organization for the Rehabilitation of Invalids and with other organizations of a similar character in various countries around the world.

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CORRADO MANNI

Telemedicine: A New Approach to Helping the Disabled

Continual technological development, which has been especially rapid in the sphere of electronics and computers, has led over the last few years to the creation of especially advanced systems. The possibilities which these systems hold out in the sphere of telemedicine have become ever more interesting and exciting.

This modern discipline, indeed, thanks to the combined technological opportunities afforded by computers and telecommunications, has created the bases for a closer relationship between health structures and patients. At one time this was only possible through admitting the patient to hospital, with all the obvious human and social consequences which were necessarily involved.

In our country, despite certain rather discouraging starting points, numerous expressions of telemedicine have already emerged into practical day. Only a few of these, however, have got beyond the experimental stage. Amongst the most important one can cite the systems of telecardiography—such as the cardiotelephone and the cardiobip; teleelectroencephalography; teleconsultation; teleanalysis; teledialysis; and the hospital car.

The common denominator of these services is their ability to deal in good time with that monodirectional or bidirectional flow of information which moves between the patient and the non-specialist on the one hand, and the highly specialized medical centre which is far away on the other. This is very important first and foremost in those areas where there is a marked dispersion of resources within a given territory and where, as a consequence, not all the citizens can take full advantage of what our health system has to offer.

This is not a question, it should be made quite clear, of mechanizing health care—the human element which is present is and will remain essential and irreplaceable. The goal is to maximize the professional capacities of the health care workers and to help to make their work more effective and speedy. In this way the quality of the service and its accessibility to citizens, not to speak of its cost-effectiveness and efficiency, will be raised and improved.

A special area of application of these instruments and services concerns disabled and handicapped people. One is dealing here, as is all too obvious, of a social reality where suffering is often bound up with hardship—something connected both to the intrinsic clinical condition of the person involved and to the state of isolation which frequently goes with it.

There is an evident need, therefore, for a new awareness and concern towards this part of the population. This new attitude should draw upon the human and technological resources which our country is able to offer. A special round of applause should go to the SIP which, for some time, has been engaged in an ambitious program

of social telephony specifically aimed at old people and the handicapped.

The increase in the aged part of the population is by now well known, not least because of the important socioeconomic consequences which this phenomenon has provoked. Recent statistical analyses show that in European countries the percentage of people over sixty-five is roundabout fourteen per cent. This percentage will increase over the next decades to such an extent that it is thought that the rate will exceed twenty per cent by the year 2030. With regard to disabled people, it is calculated that people with some kind of handicap—sometimes caused by age itself—now constitute about fifteen per cent of the total population.

Unfortunately, still today, notwithstanding the socioeconomic growth which has involved ever larger parts of the population, disabled people often exist in a state of social isolation, both with regard to their own kind and in relation to the social services. With the use of the most advanced forms of telematic technologies, however, it is now possible to create systems of communication which can break down this wall of noncommunication between the handicapped and normal use of the institutions and services available. Technological development now allows, indeed, the use of ever more flexible and valuable networks which can increase the utilization of the services which are offered and give rise to suggestions as to the creation of new ones.

The questions which are still open in this field concern both the technical aspects of the user's terminals which must be able to deal with the specific needs of handicapped people, and the organizational aspects which are fundamental for a correct functioning of those systems of communication which are used for these purposes. In order to offer a general survey of the main services which telemedicine and more generally telematics can provide I would like to outline the following:

a) videotelephone services for the deaf and dumb;

b) services for the blind;

c) access to multimedia services and " intelligent homes ";

d) telemonitoring systems;

e) systems of teleaid and telecare;

f) data banks with a social content;

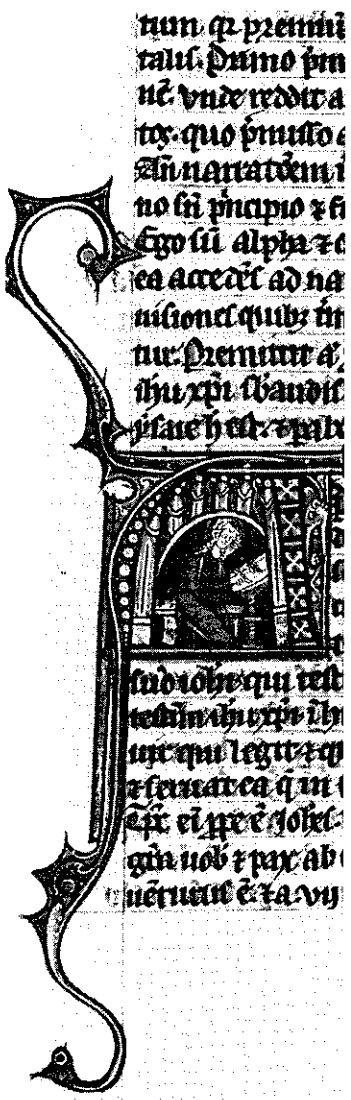
g) systems of teleteaching;

h) telework.

Video telephone services for the deaf and dumb represent one of the most immediate applications of the new possibilities offered by public telephony. Through video telephones and with the use of sign language it is in fact possible to achieve communication between the deaf. In using the public network ISDN (integrated service dialling network) the video telephone enables deaf people to communicate directly both with other deaf people and to use a service centre manned by interpreters. These interpreters deal not only with translating spoken language into sign language but they are also able to offer information and help in matters relating to health, social problems, and daily life. For example, the personnel at the service centre can call a doctor and help him, if the need arises, in his discussion with the deaf and dumb person; can provide information on means of transport; can make hotel bookings; and do many other thing as well.

In July 1991, in the city of Turin, an experiment took place involving a pilot scheme of communication between deaf and dumb people and of interpreting between the deaf and those with normal hearing. The service centre is equipped with a normal telephone, a videotelephone, a videotel terminal to gain access to a electronic data bank, a television for the televideo service, and a paper archive for information of other kinds.

Services for the blind, as a result of modern software and hardware based on a correctly used and projected personal computer, allow the user to have an interface aimed at an improved integration of blind people in the social and productive fabric of society. The most important objectives in this sector are the creation of apparatus which permit the reading of written texts through systems of immediate recognition of characters and their subsequent vocal expression. At a more general level, the development of vocal interfaces involving both input and output of information provides a better interaction between man and



machine and seems to be useful for other categories of disabled people as well. The use of the voice, indeed, can allow the user to give commands to the telephonic apparatus such as selecting the number desired or answering an incoming call. The blind person, in this way, can use all the normal telephone services by using vocal commands alone; he can receive not only normal telephone communications but can also, by using the computerized vocal expressions, listen to the reading of books or newspapers.

The concept of " intelligent home " involves the possibility of integrating the principal domestic machinery and equipment dedicated to communication, such as the telephone, the television or other domestic instruments used in usual domestic activity, within a digital network controlled by a personal computer. The spread of the ISDN network could provide a technological infrastructure for access to multimedia services of the number network such as the videotelephone, the digital telephone, the advanced fax machine and so forth. Service centers could be equipped with systems of telecontrol and telecare which are especially useful, as we will see, with old people and the disabled. Vocal recognition and interface systems directed at particular categories of handicapped people will allow these people to have an improved integration into their domestic environment and better links with the outside world. Thanks to this equipment and machinery, indeed, the disabled person would be able to achieve an easier and safer management and use of the resources of his own home and thereby obtain a real increase in the quality of his life.

The telecontrol and transmission of medical data systems involve one of the more classic aspects of telemedicine. Through them, the clinical state of a patient can be subjected to control without the patient having to leave his own home. The evident advantages for the handicapped person are more than obvious. One need think here only of cardiotelephone systems which allow the long-distance transmission of electrocardiographic signals to listening centers manned by specialist doctors who can make a speedy assessment of heart problems

In addition to the by now famous cardiotelephone, special mention should be made of the so-called " cardiobeeper. " This is an instrument of very small pocket size which can record, remember, and transmit the ECG signal. Given the very small size and the battery-run character of this gadget, the cardiobeeper can always be carried around by the cardiopathic patient. At the moment at which the heart patient notices a disturbance he must place the electrodes on the gadget on the precordial region and press the button. Afterwards, through a telephone, he can transmit the recording he has made to the listening center, where it can be analyzed by the cardiologist.

Mention has already been made to systems of teleaid and telecontrol—as is clear from the terms involved, they allow the disabled person who lives alone or who finds himself temporarily alone at home to defeat his own isolation and the risks connected with it by means of a far-off assistance center. One is often dealing here with people who are relatively self-sufficient but who may need that help—usually only periodically—which enables them to overcome possible problems without having to go out of their own homes. The system of teleaid is based upon a remote control which the user always carries with him and which is connected by radio to a linked receiver which, in turn, is joined up to a telephone system. When the need arises, or when danger threatens—as, for example, in the case of the person feeling ill—the user merely actives the remote control. The receiver sends a coded message along the telephone network to the listening center, which is thus able to identify the caller and take immediate suitable steps. At the same time, the computer which deals with the matter registers the call and presents data on the person involved. This is very useful in providing information of a character which has already been outlined. The operator can put himself into contact with the user to find out the reason for the call and can therefore take the necessary measures like calling a doctor or an ambu-

lance or directly activating the systems of aid when they have not answered his call.

The domestic telecontrol system is, instead, a number of telephonic contacts which are activated by a service centre which regularly checks up upon the needs and the psychophysical condition of the patient. In this way a friendly and trusting relationship is established between the operator and the subject which is very beneficial for the latter in both practical and human terms. Some teleaid centers are already operational in Italy, especially in the centre-north regions In the Veneto region the teleaid and telecontrol system exists in more than five hundred communes and helps over thirteen thousand people.

Data banks containing information of a social kind are another interesting example of the application of telematics to the problems of handicapped people. In Italy it has been operative for a number of years in Milan at the Don Gnocchi Foundation—SIVA, or (in English) Auxiliary Assessment and Information Service. The contents of this data bank are essentially of a rehabilitative character: the information helps in finding and providing materials and instruments which serve to lighten the handicap of a sick person, such as simple apparatus to wield objects or computer vocal systems. The SIVA data bank is the Italian pole of the Handynet project of the European Community Commission Its aim is to create an integrated and multilingual European system of information on the subject of disability.

Computer aided teaching and teleteaching constitute a very worthwhile help for children with impaired hearing—their development and their integration into the rest of the class are fostered and promoted. It has, indeed, been demonstrated that a computer equipped with suitably researched programs can enormously help the linguistic acquisition of children who are deaf and dumb from birth. Educational programs have been created in Liguria and are today available to schools and ordinary citizens. Through the videotel service of SIP it is indeed possible to have access—even from far away—to a vast number of didactic programs devoted not only to the linguistic area but also to fields concerned with geography, history, mathematics, and logic.

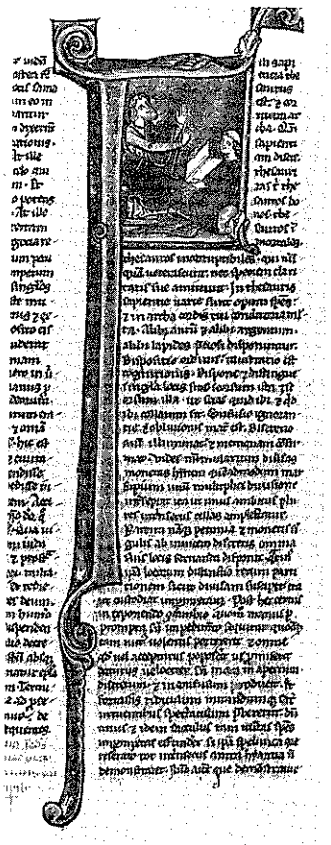
As a result of what telematics can offer, the distance which separates the handicapped person from the world around him can also be shortened in the world of work. It is, indeed, possible to create jobs which use the normal telephone network and thus allow work activity in places other than the office, such as one's own home. Such jobs rely upon a personal computer and other instruments such as a fax and a videotelephone which involve the large-scale exchange of information, at times even of a visual character In this way the person who is afflicted by a motorial handicap can perform his job in his own home without having to put up with tiring and difficult journeys.

The importance of all these matters in the world of today is borne out in a very significant way by the attention devoted to communications and handicap by the National Program of Research on Telemedicine. This program, which is sponsored by the Ministry for the Universities and Scientific and Technological Research, seeks to develop highly innovative and strategic technology in the field of telemedicine which can be applied to the world of industry in the medium term.

The fundamental objectives of the program are the following:

Firstly, to promote the development of a comprehensive strategic picture aimed at identifying those initiatives taken with regard to specific sets of problems in the sphere of health policy and care which use the technology of computers and telecommunications. The purpose of this is to obtain an effective qualitative improvement of health care and to achieve a real improvement in the quality of life, especially in the southern regions of Italy.

Secondly, to identify the main conditions which can promote and foster the growth or aggregation of scientific skills and aids which can stimulate the interest of public and private centers which operate in this area in technology which is eminently innovative and advanced. And, furthermore, to promote the development of practical productive realities in relevant sectors



which can effectively deal with international competition.

As has already been observed, a specific part of the program is directed towards the social sphere and more precisely towards auxiliary systems for communication by disabled people. Research and training activity connected with this area should, indeed, deal with the development and creation of auxiliary systems which can enable handicapped people to communicate with normal users and to have access to information supplied in special forms

Four areas of applied research, in particular, are envisaged. The first concerns the development and creation of a system of communication based upon the nascent service of public videotelephones which can enable people with severe hearing deficits to communicate both with each other and with those with normal hearing. The system involves the use of interpretation centers and utilizes acquisition and digitalization procedures for the presentation of images which guarantee the perfect intelligibility of information communicated by sign language or lip reading.

The second is the development and creation of an integrated system of telephonic communication between subjects who have very serious speech and hearing handicaps and normal users. The system is equipped with a user interface which can also be employed by people who have motorial handicaps affecting their upper limbs and involves the input of textual messages and their subsequent conversion into vocal signals suitable for transmission through the conventional telephone network. In contrary fashion, the system is able to convert the oral messages communicated by a normal user into a written text which is then displayed on a screen which can represent both letters and numbers.

Another area of research concerns the development of a system aimed at the reading of texts to blind people. This system involves the acquisition of written texts such as books or newspapers in character form, their recording, and then their conversion into oral form using machines of automatic synthesis. In addition, this system should be able to link up to both local and national programs of videowriting through the telephone system.

Fourthly and finally, the development of a system of telephonic communication confined to the use of people who are affected by serious motorial handicap to their upper limbs is envisaged. This system should be able to be used through simple oral instructions which are given directly by the disabled user. The gadget by which the voice is recognized is characterized by a high standard of reliability and independence by the characteristics of the vocal signal of the individual user so that it can be used with ease in normal environmental conditions.

The National Program of Research into telemedicine opens up new prospects for development and progress in this delicate field and enables us to be confident about a possible future expansion in the range of use of these services and this advanced technology.

The overriding objective is to overcome all forms of barriers and obstacles and guarantee the achievement of adequate and suitable care and treatment in all sorts of situations and in all kinds of places.

We are convinced that the achievement of this goal will contribute in a significant and meaningful way to an improvement in the quality of life of handicapped people and will foster and promote their full integration into society.

Before concluding, I would like to make one last observation. Telemedicine was born and took its first steps in the industrialized countries alone, in places where the health services were already very highly developed. In fact, it offers its greatest room for effective action in the poorest countries and in the most disadvantaged areas, in places which are characterized by a marked lack of suitable structures and specialist doctors and by very high levels of need with regard to treatment and care.

In this way, telemedicine sees itself as a possible solution in providing an acceptable health system and in eliminating those inequalities of an ever growing size which compel the majority of the world's population to be deprived even of the right to health.

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JAVIER OSÉS

Voluntary Service by Christians

Introduction

1. The central subject of this seventh international conference organized by the Pontifical Council for Pastoral Assistance to Heath Care Workers is " handicapped people in our society. "

The subject has been considered in all its personal, social, scientific, technical and moral aspects in a true interdisciplinary dialogue.

In this short paper, which is to be seen as within the concept of man which animates this conference and which bears an explicitly Christian and ecclesial imprint, my contribution has a simple and practical aim—the stimulation and encouragement of voluntary service for handicapped people within the ecclesial communities.

The Voluntary Work Under Discussion

2 Voluntary work, as an organized service and with well defined objectives and practical functions, is a relatively modern institution which is well established in many countries of the world.

It is universally present as a service as a response to serious social, family, and personal needs both of individuals and of groups within our society. The field in which it is prevalent is the vast world of health care and health. Voluntary work, as a free and generous help for people who are in a state of absolute necessity is as old as man himself. Throughout the history of humanity, in all cultures and latitudes, there have been people with compassionate hearts who have been ready to help those who are in urgent need.

Starting with this universal voluntary service we have arrived at what in our age voluntary service—in a narrow sense consists of. Such is the subject of this paper.

The different levels and degree of voluntary work may be listed:

a) There is a spontaneous, elementary, and primary voluntary service. It springs from personal good will as a response to the manifold needs of individuals who find themselves in the situation of not being able to deal alone with their very serious precarious condition.

Seen from the point of view of Christian faith, this voluntary service is a way of practicing Christian charity, a concrete expression of the commandment of love drawing impulse from the Spirit.

This voluntary service, which we can describe as basic, is spontaneous and has in its very basic structure the most essential elements of voluntary service in a narrow sense.

The Church, in her ordinary pastoral action proclaims and promotes this voluntary service as one of the primary requirements of that faith which expresses itself through love (St Paul, *Gal* 5:6).

b) A second form of voluntary service is that which is also born from spontaneous, personal initiative but which has characteristics that deserve our consideration.

This voluntary service is engaged in constant development and is carried out by people who are part of a institution, such as a parish, a hospital, a centre for handicapped people, or a centre for the elderly.

It encapsulates the values of generosity, free-giving, and dedication. However, because the person

involved finds himself in an environment in which the social realities are more complicated it also requires a certain Christian judgement and perception.

The reasons behind possible objections to certain ways of carrying out this voluntary service lie in the fact that the individual's attention can stray from the basic problems which are frequently present and which can not be ignored. I am speaking here of situations of true and authentic injustice, of violations of human rights which can arise in the field in which voluntary work takes place.

Obviously enough, good will and generosity are not enough. Love is real love when it advances justice and promotes the dignity of people in their actual circumstances.

The Church, with her pastoral solicitude, asks that these initiatives of a voluntary character are coordinated and are chosen according to criteria by which those who carry them out have in mind the fact that they are active members in a co-responsible Church

c) These reflections bring us directly to what is proposed as the aim of this paper—the putting into practice and the promotion of voluntary service which is correctly organized in line with the spirit of the Church.

One can adopt the definition of voluntary service given by Luciano Tavazza and by Caritas which, in my judgement perfectly captures all the fundamental elements concerned: " A voluntary worker is a person who in a disinterested and regular fashion, in addition to his professional and natural duties, dedicates part of his time and his activity not to himself or of those around him but to other people or to matters of collective social importance,and does so according to a plan which does not finish with the action itself (as occurs with charitable donations) but which seeks to destroy or modify the causes of the need or the social marginalization ".

This is a definition which, as can be seen, is clear in its expression, rich in content, and which deserves to be considered, investigated, and absorbed until our voluntary service is the commitment of an evangelizing Church of today's world

Social and Ecclesial Reasons for Voluntary Service

3. Different methods can be chosen to meet the purpose of this paper—that of making people feel invited to promote Christian voluntary work.

One of these could be that of pointing out the different features of Christian voluntary work, or rather the requirements, the motivations, the functions, the training, and so forth.

Leaving aside this choice because voluntary work has already by now acquired obvious forms and because the time available does not allow me to consider the subject in suitable fashion, I will limit myself to presenting some of the social and ecclesial reasons which justify and are asked of the voluntary service of today.

The social reasons which I shall mention are, however, in perfect harmony with the Christian message and therefore must be respected and accepted.

A. *Social Reasons*

Voluntary work gives certain human values of great humanizing power to society, and more specifically to certain people and social groups who are victims of dehumanization—that is to say the sick and the handicapped.

They are the values indicated by the definition given by Tavazza and Caritas: free and regular service, generosity in renewed tension, the spirit of sacrifice, work in favor of social and collective interests which foster, promote and influence the transformation of society having the aim as they do of destroying the causes of major needs and marginalization.

Voluntary service is by its very nature something which can be done by many people who can be its active agents. Many of those who suffer from serious need, physical or mental limitations, or marginalization, can find in this voluntary service a convenient answer to their difficulties.

It is, in social terms, a universally accepted value because it is exclusively directed towards service of the person in need, and goes beyond any ideology, faith, or particular interest.

In a democratic and pluralist society like ours, voluntary service becomes a privileged point of convergence of social pluralism.

The expression of awareness of the dignity of the individual enlarges the range of services required for that dignity.

In a society in which the state constantly increases its role with damaging consequences for the principle of ancillary initiatives, that society itself must fill that which is necessarily created through use of private initiative.

One example suffices. Bureaucracy hinders the urgent and rapid finding of a solution to serious personal or collective problems. The absolute priority of the individual requires, however, that a solution is rapidly reached. To achieve this end, therefore, the help of the voluntary sector is required.

But we should add that the action of this sector must, in its turn, bring pressure to bear upon the government so that it resolves the problem which is, at base, its responsibility.

As its goal voluntary service aims at the promotion of the individual and groups with the clearly defined

goal, however, that it is the individuals themselves who must take the front seat in achieving their own global development.

In this sense, voluntary service is an authentic educational and self-educational mission which makes a contribution to the highest development of the potential of the individual.

Voluntary service works with people, without, however, taking the place of their protagonism which, indeed, it strengthens and reinforces.

B. *Ecclesial Reasons*

Given the above-mentioned values and those to which the definition of Tavazza and Caritas refer, does it not appear evident that one is dealing here with a whole program of Christian militancy for all those who adhere to such values with faith?

Is it not perhaps, an example of the style of the Christian which is so happily described by John Paul II in *Christifideles Laici*?

Voluntary work is a very simple and practical way of expressing love to one's fellow man, and of giving concrete form to the commandment of love which is the defining sign of the Christian.

Voluntary work supports the Christian logic of being and substitutes that of having which is characteristic of our consumer society. It stimulates Christian values which move in a contrary direction to those which dominate the man of the contemporary age.

Social relationships are often based upon mercantilism. The Christian voluntary worker, however, in a way which expresses the union of hearts and life, upholds the model of free dedication and seeks to put into practice the word of the Lord Jesus: " It is more blessed to give than to receive " (*Acts*, 20, 35).

Voluntary service, in following the advice of Paul to take into consideration " whatever is true, whatever is honorable, whatever is just, whatever is pure, whatever is lovely, whatever is gracious, of there is any excellence, if there is anything worthy of praise " (*Phil* 4, 8) engages in work because what is there of greater truth, nobility, and good than offering a free service to those who need others in order to keep going?

The Church, which is an expert in humanity and whose way is man, must show her interest in all the problems and difficulties of man. It is time to end misunderstandings such as the idea that the interests of the Church are contrary to man.

We must show—and voluntary work is an excellent way of doing this—that our interest in man and the basis of our Christian faith is to believe in a God who is on man's side.

In our mission we move in spaces that greatly affect the problem and difficulties of man such as, for example, those of social marginalization. In an apathetic world the moment has come to offer man reasons to live and to hope. In this area, voluntary work can render a very great service.

We must re-acquire within the Church that authentic moral teaching which puts the commandment to love at the centre of things.

Let us show with facts that we are the Church of the poor, that our principal choice is indeed them, that in a civilization which exalts the winner we are with the defeated, with the marginalized, with those who are worth nothing and count for nothing.

Is not voluntary service a form of struggle for the total liberation of man—something very much wanted by the social teaching of the Church?

The sensibility of present-day man, in conjunction with the teaching of the social doctrine of the Church, has brought us to the conclusion that we can not help a man in need with a stance of donation when what we should give him is justice. Justice and charity are not in antagonism but complement each other.

The first duty of charity is justice because love for a person is expressed first and foremost in respect for that person's rights.

Seen from this perspective, voluntary service, as we express it, is a clear commitment to struggle against injustice—" it seeks to destroy the causes of need and social marginalization " (Tavazza and Caritas).

Many needs of many people can not be met with money or with an abundance of material resources. There are essential needs, of vital importance for the individual, which can be satisfied only through values such as love, solidarity, understanding, human warmth, presence, being able to listen, and company. These values are what constitute voluntary service.

Conclusion

I will finish my paper with an expression of the wish that our Christian communities discover, promote and animate voluntary work which serves handicapped people or the other manifold social, familial, or personal needs which exist.

It will be a sign of a Church which wants to evangelize and wants to appear to the world as the Sacrament of Salvation. It will open a sea bed for charitable action on behalf of the Church and for the promotion of justice in the world.

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Bishop of Huesca, Spain

FRANJO Cardinal KUHARIC

Spirituality and Rehabilitation

" If for this life only we have hoped in Christ, we are of all men most to be pitied " (*1 Co* 15:19).

The subject which I have been given is " spirituality and rehabilitation ", and I interpret this in the sense of the spiritual rehabilitation of those who live in a state of tribulation and trial.

Let us try to enter the innermost part of man, his soul and his heart. In what ways does a man in this area reflect his situation? For example, a man afflicted by an incurable illness, or a man injured and handicapped for life. How does he manage with such a limited and constrained existence. He is limited as far as regards his work opportunities, his movements, and his relationships with other people. He lives out a different life from that of other men. They are healthy and active. They work, they take part in social life, and they have a large range of satisfactions which are denied to handicapped people.

How does the man who is blind from birth manage his blindness and his unending night which never gives way to the dawn? Can men who can see understand how a man who has been blind from birth goes about feeling his world?

How does a man who is condemned to immobility feel about his life? Can healthy men understand the state of the soul of a man who is rendered immobile?

During this terrible and aggressive war which broke out first in Croatia and then Bosnia and Herzegovina, and which has sowed so much terrible destruction, the number of dead and injured has increased enormously. In visiting the injured in the hospitals and many destroyed buildings I have seen human beings, young and seriously injured people, without their lower limbs, without hands, without eyes, immobilized by damage to the spine, and with very great injuries to the intestines. At the beginning these injured people displayed a certain optimism because they had sacrificed their lives to resist unjust aggressions and attacks, to defend their liberty, their homeland, and their homes. The knowledge that they had not occupied other people's lands, that they had not wanted to oppress other people, gave them strength to accept their condition. However, with the passing of time, when they came to fully realize that they were mutilated for life, they began to ask themselves and others a disturbing question: what is life for? What will the future consist of? What will happen to the family? In the case of people who are not yet married there is the question of whether it will be possible to create a family. What is the meaning of all this?

Thus it happens that in the case of sick people, and above all of those who are terminally ill, very seriously injured, and invalids, there arises a special psychic state of mind which is only understood with great difficulty by people who are healthy and well.

What should one say to these people? How can their spirit be

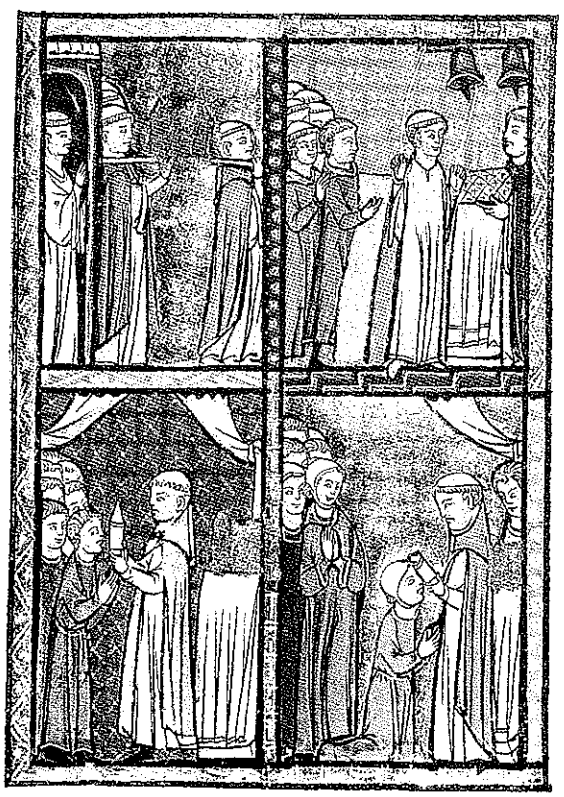
touched by the rays of hope? How should they be told about the meaning of their lives and suffering when, above all else, there is no hope that their condition can get better? A medical doctor, with his professional skills, can help them. He can reduce their pain. The psychologists will seek to give them their confidence back using his methods and his experience. Healthy and well people will go on surrounding them with care and concern and offering them all the help they can give. However, the fact remains that that person bears his cross alone. What attitude and approach, therefore, should be adopted towards him?

Behavior towards one's own suffering can take many forms. Very deep anxiety and rebellion can take place: why me? Or there can be apathetic resignation and a sense of hopelessness. There can be an acceptance of the cross, but coming from what strength and what kinds of arguments? The testimony of so many suffering people proves that it is possible even to experience joy at the same time as such suffering. But for this to take place a deep spiritual life rooted in faith, hope, and love is required. The man enlightened by faith in Jesus Christ who was crucified and rose again; the man who, with full faith in the love of God, discovers the meaning of life and of his own suffering—that is the man who can accept his own cross as a pledge of sanctification.

The Holy Father John Paul II, in his apostolic letter *Salvifici Doloris*, developed the theology of suffering in the light of the Cross and the Resurrection on Christ.

In order for a spiritual force to be vital in the terminally ill, the injured, and the handicapped, they should engage in an authentic relationship with God in faith and with trust. Divine revelation is the only answer to the deepest questions about the existence of man: what is the meaning of human life? Is this meaning something that ends here between birth and death? Is the meaning of human life something which belongs only on earth and in this historical context? Or is it something which goes towards an absolute future of a new land and new skies, the dwelling place of justice? (cf. *2 Pt* 3:13)

Materialism, wherever it comes from, rejects the idea of a spiritual dimension to man. It denies the out-of-time meaning of human life, and for this reason it cannot offer hope to man, and especially to the man who is afflicted by suffering.



Jesus Christ, who was man made God and was born to the Virgin Mary, took human form so that He could experience the human sufferings of the spirit, the heart, and the body, and with such an experience and with his death He could be nearer to every man who suffers. With his resurrection He placed a new light in the spirit of the person who suffers because it announces the possibility of eternal life in joy and love and the physical resurrection of our mortal body which, like his glorious body, will be mutilated and injured.

For this reason the spirituality of the person who suffers must be constantly permeated by faith in eternal life and in the resurrection of the body. This is the fundamental truth of the Divine Revelation regarding man and his meaning, and it is this truth which drives away the darkness of suffering and death. In the light of this truth, human life acquires a meaning even when it appears to be meaningless to men.

In addition to the foregoing, within the spirituality of the man who suffers there must also be the mystery of love. "For God so loved the world that he gave his only Son, that whoever believes in him should not perish but have eternal life" (*Jn* 3:16). Sin is the perdition of man. Sin is man's greatest calamity because with sin man breaks the bonds of love between God and man. Sin is the seed of the eternal perdition of man, the eternal failure of the existence of man, and all this is an eternal existence deprived of meaning. But God so loved sinful man that for his sake he became man and died upon the cross. God's love for us shows itself in the most unthought-of ways—in suffering and death upon the cross. Each of us has to ask himself: in what ways has God loved me? He has loved me like this: he opened his arms and died for me! His pierced heart is a sign of this love. He took upon himself our sins and our sufferings. This love is the means by which our sins are forgiven. With this love he sanctified our sufferings as well so that they also could be a testimony to our love for God and for men.

The most important element in the spirituality of suffering people is an identification with the suffering crucified Christ so that they can also identify with Christ's redemptive love of the world. Through this, suffering takes on a mysterious fertility. In union with Christ, the suffering man saves many of his brothers and takes part in the mystery of the Redemption. In this way, suffering can become an interior spring of joy because it has becomes life and love.

I would like to take a example from my homeland. A man blind from birth named Michael, at the age of sixty-three, gave an interview to Catholic newspaper. The journalist, who was a priest, asked him how he came to accept his blindness, an eternal darkness which had never allowed him to enjoy the light of the sun, the color of the flowers, or the face of his own mother. Michael replied, " Father, I have thought about this for a long time and I have often asked myself, 'Why can I not see like other men? Why has God denied me the light of the sun while others enjoy it without ever thinking of the very great gift that they have received from God? I believe that God has made me a great gift of not being able to see the light of this world because he wants me not to lose the divine light of the celestial kingdom. God never does anything without a specific end in view. The most important goal is to enter into paradise. In this way, after listening to the Gospel story of the man blind from birth, I came to my conclusions . . . While the healthy man works and goes about his business, I gain advantage from the Church and the Holy Mass in my quest for the Holy Gospel. It was in this way that I grasped the meaning of life. . . I thank God, because he has saved me from spiritual blindness " (*La Chiesa sulla Pietra*, no. 11/87, p.14).

This is an example of what heights of rehabilitation and spiritual maturity a man who suffers can arrive at when he links up with the force of faith, the force of prayer, the force of the sacraments, and when he dwells upon, and contemplates, the word of God.

Those suffering people who have such a spiritual life are an authentic source of richness within the Church herself.

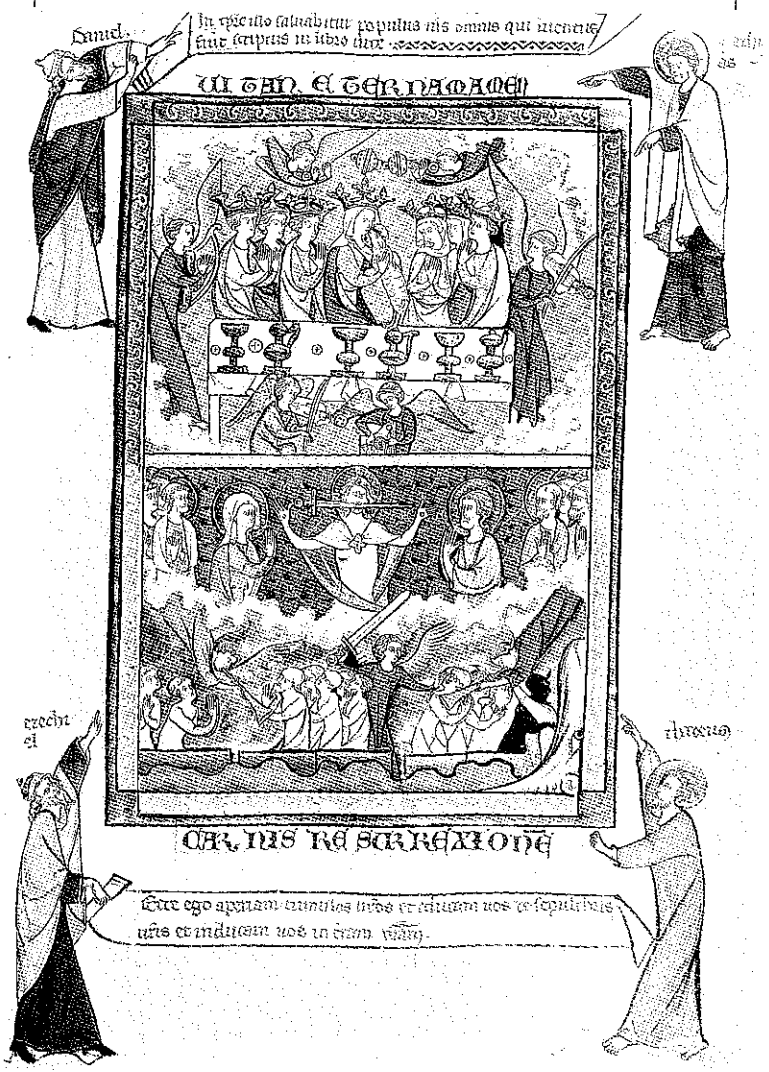
In his apostolic letter *Salvifici Doloris* the Holy Father writes, " The Church recognizes in her suffering brothers and sisters a rich carrier of supernatural strength. Thus it is that the pastors of the Church confide in them, and seek help and support from them. Those who take part in the suffering of Christ bear an exceptional particle of the inexhaustible treasure of the Redemption of the world in their personal suffering, and it is in this way that this treasure is communicated to other people " (no. 2). In this way their suffering is touched by the greatest of loves and becomes love!

One final observation! It is no accident that Christ has made so many saints and good men participants in his suffering, and in an especial way the Virgin Mary, his mother! Was not the life of the Virgin, perhaps, a constant process of suffering? Was her heart, like the heart of Christ, not a dwelling place of love and suffering?

Does not the suffering man attain the zenith of his spirituality when he accepts his own suffering as a choice of God and a call to take part in the redemption of the world?

FRANJO Cardinal KUHARIC
Archbishop of Zagabria

Round Table



The Disabled Around the World: Witness

CLAUDE TRONTIN-DREUX

The Intercontinental Christian Brotherhood of Sick and Handicapped People

Introduction

The Intercontinental Christian Brotherhood of Sick and Handicapped People is a movement for evangelization. It is the work of sick and handicapped people which has received a mission from the Church to reveal the Good News of a God who is love and life to sick and handicapped people. Trusting to solidarity and a fraternal evangelical spirit, the movement seeks the complete fulfillment of these people, their integration, and their full participation in the life of the world and of their Church. "

Today I am here to describe this witness to you in the name of the International Christian Brotherhood of Sick and Handicapped People.

This brotherhood is over forty-five years old. It has spread to four continents and is present in forty countries all over the world. It was founded by a French priest, Father Henri François, who died in 1960. His prophetic intuition was the following:

In every person, however handicapped he might be, capabilities always overcome the evident limits.

Every person, however handicapped he might be, is capable of action and of love.

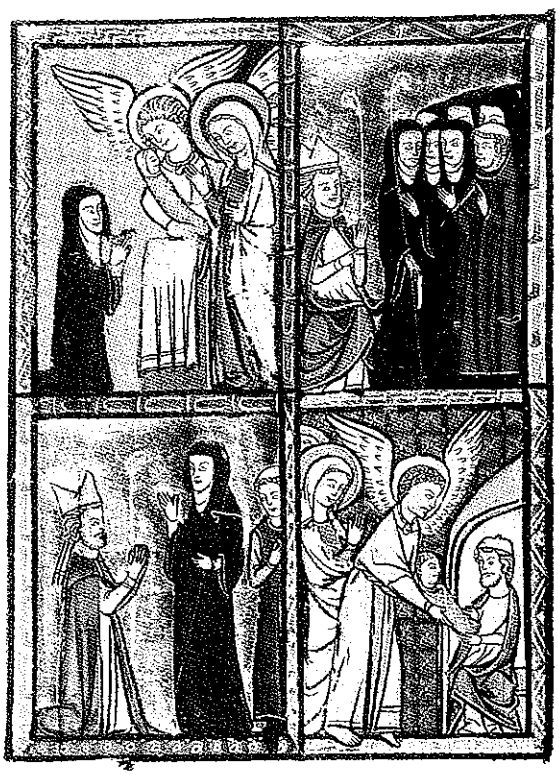
Every person, however handicapped he might be, is called upon to pass from being helped, and from taking, to involved responsibility and service.

In every person, however handicapped he might be, capabilities always overcome the evident limits

At the beginning, for the Brotherhood, there is always the path of a handicapped or sick person who draws near to another of the same description. His handicap could lead him to shut himself up within himself. Certainly, this would be more convenient and comfortable for him. To draw near to another person, to meet him and to help him, already amounts to a move away from one's own self-centeredness. It already means going beyond one's limits—it already means " Brotherhood "!

Thus it was that in a French city, a physically handicapped girl found herself in a hospice for elderly people. For quite a long time she struggled to leave the place and to achieve her own independence. She had to demonstrate to those in charge of the hospice that she was able to live an independent life. Once she had obtained her independence she did not remain inactive in her newly won condition. On the contrary, she regularly went to visit her friends who had stayed in the hospice. She went to stimulate meetings between these people and to help them to leave that arduous environment. She wanted them to experience authentic freedom.

For the Brotherhood a mere going beyond one's own self-centeredness is not enough. Meeting other people is always a matter of " engaging in community. " It always means the construction of a fraternal group: life, experiences, difficulties, and riches of various



forms are all shared. There people discover themselves, their own possibilities, their own values, and their own problems.

To give another example, there is a young Madagascar boy aged twenty who is confined to a wheelchair because of polio. He is a student. Every weekend he travels kilometers, using only the power of his arms, in order to meet the sick and disabled people of his neighborhood and of his local parish. Today he is the person responsible in the diocese for the Brotherhood—he is active, diligent, and always on the ball.

Every person, however handicapped he might be, is capable of action and love.

The following sentence of a Latin American authority is uppermost in the mind of all of us who belong to the Brotherhood: " Illness or handicap are not an excuse for taking part in the construction of a better world. We will not be judged according to our intentions but according to our actions. "

Does the fact that the author of this phrase is a tetraplegic not mean a great deal? The sick and disabled person is the best placed person to encourage other sick and disabled people to come out of their shells and to become fully responsible protagonists. Human resources are not only to be found, and are not to be found first and foremost, in legs and arms. They are to be found in the *human will.* Our aforementioned friend, who has been confined for years to a wheelchair, traverses the *whole of* the continent of Latin America and the Caribbean. He writes and publishes books. Everywhere he goes he meets people and sets up groups. Everywhere he goes he meets bishops and civil authorities. The same declaration is made everywhere: the sick and disabled person is, before everything else, like every other person, capable of creative love. He is inventive and responsible. The Brotherhood wants to say to *everybody* those words that Jesus spoke to the paralyzed man: " Rise up and walk " (*Mk* 2:8-12).

Every person, however handicapped he might be, is called upon to pass from being helped, and from taking, to involved responsibility and service.

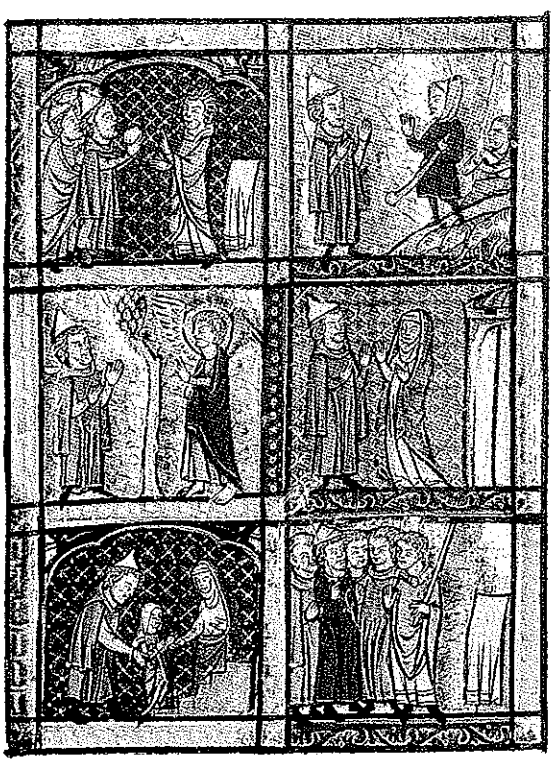
In our opinion what matters here for modern society, in the form it takes in developed countries, is *taking.* A society which takes and ever increasing care of its members gives them something much more than mere *taking.* What, indeed, are the values of what we now call the developed world? They are often health and beauty, power and wealth, pleasure at all times and pleasure now. How can sick and disabled people find themselves at ease in such a context?

Let us consider a sixteen-year-old girl from a European country. She gets up one day at six-thirty in the morning to go to recite the rosary. Along the way she is involved in a serious accident—her spine is broken. Thus she becomes paralysed for the rest of her life and is forced to stay lying on her front. In hospital a nun helps her to *accept* her handicap—it is a gift from God! Something to save the world, with the crucified Christ.

At our Brotherhood our friend discovers that she has many things to do in the world; and that the first on the list is certainly not the passive acceptance of her handicap. She dedicates herself to society and seeks to improve the conditions of life of disabled and sick people.

These people are responsible. For example, they must be able to move themselves around easily, even if they are paraplegic. These very human attempts and efforts are at the root of the Christian life of our friend. She makes them in a reflection of the true light of Christ. She wants to make her brothers and sisters capable of their same reflection. In the Brotherhood of her country she becomes the national director of the education committee. This testimony shows just how much those values which our modern world holds so dear must be relativized—that is to say, put in relation to what constitutes the real center of that form of human life which Jesus called upon us to lead. Let us listen to St Paul when he tells us about the fruits of the Spirit. They are love, joy, peace, patience, kindness, generosity, forbearance, gentleness, faith, courtesy, temperateness, and purity (*Ga* 5).

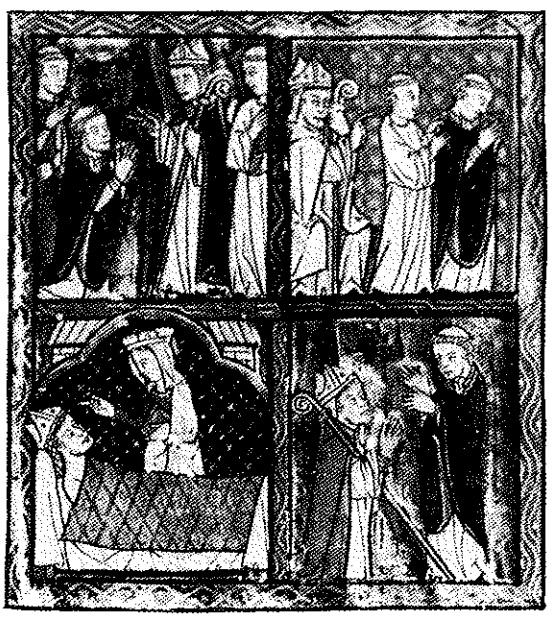
Our friend seems really to have, *in truth*, understood St Paul. On the other hand, it is only this truth that should be presented, before all others, to our brothers and sisters who are suffering and downcast, who are exploited and forgotten! The experience of the African Brotherhood, for example, gives us in this regard a very powerful



testimony. A group in Zaire, another in Madagascar—areas in which one does not eat in abundance—nevertheless manage to save enough food to go and feed prisoners who could well die of hunger. A large number of groups in Latin America are strongly committed to eliminating illiteracy. In this immense continent one has to fight for everything that will contribute to the freedom of the poor. Many examples could be given of these examples of witness which are to be found in all the four corners of the earth. In essential terms, they do nothing else but give life to witness on a grand scale—that of the Intercontinental Christian Brotherhood of Sick and Handicapped People, and that of a responsibility necessary to the life of the world and the Church expressed towards those who seem to be the weakest and the most limited amongst men.

Indeed, what would happen to the world of men if *effective responsibility* for things were *only* in the hands of the powerful, the rich, and the healthy? True values would be hidden and forgotten by *everybody* What can one say about these values? Deep human strength can overcome apparent weakness. Every person can discover what is inside them in so much as he can *be committed* without being *merely helped*. Every person has the same rights regarding human life: the right to education, to work, and to health. Every person has, *at base*, the same *duties*, and they are part of a *real responsibility* towards *serving* the world. Finally, what, indeed, would become of our Church if responsibility was simply a question for the strong; if only the rich could really give to other people? The Church would, in that case, be more *dominator* than *handmaiden*. The Brotherhood of Africa or Latin America are today, in an especial way, the testimonies to these Gospel truths—Jesus came to heal, not to abandon his disciples to illness. He came to integrate men into his Church, in so much as we *are all* members of a *responsible people*. Jesus did not come to call upon men to take their sufferings to Heaven. His Father sent him to share the suffering and the death of men, to *fight together with them* until the Resurrection. This is the message that all the handicapped and sick people of the earth expect from our Church. This is the message that the Brotherhood, in the Church, wants to send to all men. Is this not perhaps the message that St Paul writes to the Corinthians: " God has chosen what the world holds weak, so as to abash the strong "? (*1 Co* 1:27).

Mrs. CLAUDE TRONTIN-DREUX
Coordinator of the International Christian Brotherhood of Sick and Handicapped People. Orleans, France



SALVATORE NOCERA

Handicapped People: Living Members of the Resurrected Christ

The Apostolic Movement of the Blind is an association of the sighted and non-sighted. It has devoted itself, and especially after the Council, to the task of achieving the social and ecclesial integration of blind and handicapped people in Italy. It has done the same through the human promotion of initiatives in about fifty Third World countries where it is estimated that there are about forty million blind people. Against the background of this life experience we would like to present you with a number of observations and reflections.

The opulent world of hedonism and consumerism does not accept the living scandal of people with sensorial, psychic, or physical handicaps. Indeed, it may be observed that some sets of legislation allow abortion in the case of handicapped babies-to-be or permit euthanasia because, it is asserted, handicapped people cannot and should not be allowed to suffer. These examples, which apparently respect handicapped people are, in fact, acts of violence perpetrated by those who do not want to take part in the suffering of others. This was confirmed by a recent resolution passed by the European Parliament on the sterilization of handicapped women.

The principle that people who are " different " must not be marginalized has to be developed and promoted in the culture of today's society. These people must, in an absolutely contrary fashion, be listened to and integrated. Psychology, pedagogy, and didactic methods have by now demonstrated that even handicapped people can be fully integrated into ordinary

schools, work, and society. Unfortunately, in this area there may still be found tardiness, indifference, inadequate measures, and even opposition. On this point Cardinal Martini in his address to a recent conference declared that " to give welcome to the person who is different, to the person who is marginalized, and to the person who is handicapped, means making space for him in your own time, in your own home, in your own friendships, in your own town, and in your own laws "

The opulent society leaves little space for handicapped people but cuts back on expenses with damaging effects on their standard of living. But on the other hand it increases its expenditure on armaments which, in turn, in their use lead to a higher number of handicapped people.

Society, moreover, confines itself to giving treatment to handicapped people. But these latter, being what they are, are not ill, and resent being considered as such.

Cardinal Martini, in the document cited above, makes clear, on the contrary, that one must pass from the mentality of the person who engages only in " treatment " to a new mentality of " taking care of " handicapped people. These latter must not only be " seen in terms of their needs but must be appreciated for their value as human beings."

If this must be the cultural change which should take place within civilized society, then the cultural, pastoral and operative change which has to occur within the religious spheres and most especially within the ecclesial communities—must be even greater. Within

this last area, handicapped people are often not considered important and are not listened to, integrated, or involved.

Unfortunately, we can still see that:

Many Catholic schools do not accept the presence of handicapped pupils and suggest to the parents that they put their children in special schools. In these institutions, even if there is to be found first-rate professional teaching, these children and young people lose the richness of interpersonal relationships with class mates who are not handicapped and become trapped in a system of marginalization which prevents them from achieving full social integration;

there are very few Christian employers who attend to the needs of the work activity of handicapped people. This is despite the fact that the Pope made clear the right of disabled people to work in the papal encyclical *Laborem Exercens*;

mentally handicapped children are denied access to the sacrament of the Eucharist because, it is said, they do not understand what is involved. As a result, there is no attempt to take advantage of the advances in the didactic and pedagogic sciences in order to help them with suitable and appropriate forms of catechism;

a paternalistic and comforting attitude prevails. It would be much better to have and to follow what is suggested in the document produced by the Holy See in 1981 (the International Year of Disabled People) on the subject of the rights of handicapped people.

Too often handicapped people are considered as " the members of the crucified Christ " and presented with the hope of final resurrection as a consolation for their present suffering and trials.

And yet Christ was not only crucified—he experienced resurrection. The ecclesial community usually says nothing, or says little, about the meaning the Resurrection of Christ has, and can have, for the life of a handicapped person and for his family. But Jesus, in response to Lazarus's sister who reproached him for coming too late, replied: " Do you believe in the Resurrection? " And when she said that she believed in the final Resurrection Jesus said to her: " I am the Resurrection and the Life ".

Why does pastoral action not draw certain obvious conclusions from this article of faith and work for a new evangelization of handicapped people? Why is there only a reference to their being " members of the crucified Christ " and not an affirmation of their also being " members of the Resurrected Christ "? In this way there could be an expression of their full participation as alive members of the Body of Christ in the Easter Mystery and in the global salvific mission of the Church.

To contemporary man, especially if he is suffering, we should offer the chance of drawing close to the " Crucified " Christ through the " Resurrected " Christ. Just as Mary Magdalene met the Resurrected Christ next to the empty sepulchre; just as St Thomas recognized Christ from the holes in his hands after Christ had risen; and just as the disciples at Aims understood and accepted the scandal of the cross after the risen Christ made himself known in the breaking of bread, so contemporary man can attain a better understanding of the meaning of his own suffering if he experiences the Risen Christ in the form of a Church which is faithful to the commission given by the Risen Christ to evangelize through the witness of charity and through devotion to the weak and the marginalized.

This is the content of one of the most meaningful parts of the message given by the Holy Father John Paul II on the occasion of the Day of Celebration (1984) of the Ecclesial Community for disabled people (cf. 71, *Osservatore Romano*, 3/31/84)—the " Kingdom of God " seeks the fullness of the meeting of man with his creator and Father, but the faith in the real possibility of that meeting is expressed through works of love:

" it is for us the Church, the messianic community, to continue this work of redemption carried out by our Lord. We must work with faith so that our weaker brethren—whatever their affliction may be—may be relieved and liberated from their burdensome condition."

The cross contains an intrinsic and unavoidable orientation towards the triumph of the resurrection. The purpose of redemptive salvation is the saving of the entire human being, in both his spiritual and physical dimensions. From this springs the inescapable urgency of the Christian undertaking to precede the fullness of life and of joy which will mark the experience of eternity.

It is this anticipatory experience of the fullness of life and joy that we ask the Church to announce to us, the handicapped, and to the world, so that we can attain these things during our life on earth—putting all our talents to work and invoking, in particular, a spirit of solidarity and of sharing which must grow and express itself in the heart of civil and ecclesial communities operating at both national and international levels.

SALVATORE NOCERA
National Councillor of the Apostolic Movement for the Blind

FREDERIC TRAUTMANN

The John Bost Foundation

The John Bost Foundation has its headquarters in the Dordogne region, not far from Bordeaux. It is a private, nonprofit Protestant organization which is recognized as being of public utility and which takes part in the French national health service. It takes in, looks after, and aids in the treatment of one thousand and thirty mentally and physically handicapped people, the mentally ill, and the elderly. These people often remain in the care of this foundation for a very long time.

Does not the reality of one thousand and thirty mentally handicapped people in the same institute perhaps resemble a concentrated universe which today would be untenable. Such is not the case at all, because all the people looked after, whatever their age or sex, are subdivided not according to their ailment or disability but according to their level of independence. In twenty-one cases they have a very high level of independence. These cases are distributed between six communes in the Dordogne valley and in the city of Montaubaun, some one hundred and fifty kilometers distant. If we add to all this the fact there are no perimeter walls and no kinds of fence whatever, it seems possible to argue that the feeling of imprisonment or exclusion is completely avoided and that those who are taken care of by our foundation are, on the contrary, well integrated into the human and social landscape of our region. It is certainly true that the John Bost Foundation has a long history behind it. It was born in the middle of the nineteenth century—a century of ferment, of new ideas, of changes, of expansion on a broad front. It witnessed the birth within French Protestantism of many initiatives and foundations, whether in the social, health, educational, or missionary spheres. Jean Antoine, according to John Bost, was a clergyman of Swiss origins who, together with his parishioners of La Force, built the first home for children who were at that time called idiots, incurables, cretins and so forth. He was neither a doctor nor a teacher. Nevertheless, his intuitions, his charisma, and his organizational sense—all of which were sustained and inspired by faith—gave rise to a new task and undertaking which today still inspire our spiritual, pedagogic, therapeutic, and institutional project.

Allow me, at this point, to mention briefly some of the professional and ethical principles—all of which are based on the values of the Gospels—upon which we seek to base our daily activity amongst those we take care of. These are values—shared, incidentally by many of our believers—which give our institutional project an identity, a meaning, and a certain energy.

1. A sentence uttered one day by John Bost has become, to a certain extent, the motto of our foundation: *I welcome, in the name of the Lord, those whom everybody else rejects*. We are perhaps reminded here of He who, one Christmas night in Bethlehem, was given no space in the inn. The above cited sentence means for us, still today, that it is necessary to respond to the sufferings which are dealt with in other places in ways which are not satisfactory, and to do so in a way which is appropriate to the extent to which we are able to provide a service which is suitable and of quality. We are pained by the fact that we are able to take in only fifty people every year, as opposed to the three hundred and fifty requests that we receive annually.

2. There is an idea which nowadays is perhaps banal and fragile. It holds that handicapped and mentally ill people are fully human and made in the image of God and that they are not " the rejects of humanity or errors of creation or beings without a soul incapable of suffering " as they were thought to be in the nineteenth century and are still considered in the twentieth century. This is why one is dealing here with individual, therapeutic and pedagogic projects which are constantly re-elaborated, thought out anew, reformulated, reactivated and adjusted, and which are the true basis for our institutional project. This is precisely why there is a maximum personalization of daily life, clothes, and food, and why importance is given to each person's name, his history, his environment, his activity, and his employment.

3. *Whole people, moreover*! We do not want to be only a hospital which deals with illnesses and pathological cases. We want to be a " place of life and cure, " a place in which we take care of people, where we try to take into consideration every aspect of the personality of a man or a woman—whether it be physical, mental, intellectual, affective, cultural, social, or spiritual.

Thus it is that the nine hundred members of our staff, given that the majority have professional qualifications in different medical, technical, and educational disci-

plines, have a role and a form of presence in these hospices which is conspicuously multidimensional. In this area it is more than evident that professional competence alone, even if it is fundamental, is not enough. Nothing is truly possible without a spirit of service and welcoming, without a quality of heart, of listening, of readiness to help, without spiritual and humanitarian springs of action, but also without a spirit of research and without a critical spirit.

It is because of our concern for the whole person that we seek to provide the people we take care of (all of them without exceptions) with all possible forms of suitable therapy. In this way about one hundred and twenty wards dedicated to pedagogy and ergotherapy receive, according to the circumstances and possibilities, about nine-hundred patients. I will speak here about these alone. There are also wards dedicated to psychotherapy, balneotherapy, and music therapy. Similarly, there are also many forms of activity concerned with the creation or stimulation of sensation and feeling, or dedicated to cultural and sporting matters, or which involve socialization or entertainment.

4. We have another idea which is very dear to us—the conviction that *mental handicap, even when very serious, is not an immutable or fatal condition*. To express it differently, we believe in an ever possible improvement and refuse to give up on somebody even when it seems that there is no hope left. This is why the idea of a " project " of life and therapy is so important for each person we take care of. Very recently one of them—a girl—came up to me with a radiant smile: " I am happy ", she said. " I have a project ". It is certainly true that often the objective of this project leaves little space for a complete cure. But perhaps less important then alleviating physical or psychic suffering is the belief that the life of every handicapped person has a meaning and that our activity can never become a mere matter of control or conversation. On the contrary, it must always aim at a development of active therapies, even when they are long and continuous, even when they involve very elderly people or people who have very little independence. We have the proof—confirmed by experience—that this has a most beneficial effect.

5. John Bost gave great importance to the immediate environment, to architecture, to the aesthetic appearance of things and places. For us this is of fundamental moment. Taking care of the environment is just as important as taking care of the person " I am the doctor of things, " a recent member of the maintenance staff declared. He is absolutely right, because it is difficult for us to take in just how much the environment in which we live influences the well-being or ill-being of men. Now, what is true for us is even more so for such sensitive and vulnerable people as those who are handicapped for life.

6. Handicapped or mentally ill people, or elderly and dependent people, are a part of the human community. They are one of us. This is the reason why the John Bost Foundation has always rejected perimeter walls, fences, and barriers. In this way there is a demonstration that there is to be no marginalization, imprisonment, segregation, or exclusion of disabled people. And this also applies to those whose residence in an institution is the only form of life which is really feasible. For this reason our homes are spread throughout the villages and towns of the area and are always open to the outside. No person looked after, even those who are confined to bed, must stay in their room the whole day. Everybody, and as often as possible, is encouraged to move. The patients go shopping or to restaurants, they go on holiday with their families, or they go camping. They like to receive visitors and nobody is ever considered an intrusion or treated as a curiosity. They love the presence of the one hundred and ninety volunteers who come from all the four corners of the world to dedicate one or two months of their lives to this kind of service. These latter, for both those taken care of and for the staff themselves, are like a window onto the world outside.

Within our institution, as well, we try to develop a social life which

is as near as possible to reality. Some examples may be given: little groups modelled on the family—even if they can by no means be considered as substitutes for the family; clusters of buildings organized like little towns with streets and a central square; a wide variety of activities and jobs outside the homes which have the aim, not of producing, but of acting with the outside world, of having the opportunity—for people who very often find themselves in a situation of failure—to create and to succeed in something; a bank in which each person has a personal account; a large number of different kinds of parties which are both forms of entertainment and places where people can meet, live together, and invite members of the surrounding population. There is also our psychosocial re-education centre which is dedicated to people who have often spent a very long time in psychiatric hospitals. Everything is tried—from groups concerned with the outside buildings to those dedicated to the maintenance, restoration, or development of links of the patients with their families. When a stay with the family is not possible, numerous places can accommodate the relatives for a week or two without charge

The relationship with the Church involves the same question. It must be made clear that handicapped and mentally ill people also have their place in human society, and also, I hope, in the ecclesiastical community.

7. There is another field, which is of evident importance, which I would like to draw attention to here. It is *the taking into consideration of the requests, needs, and anxieties which are of a spiritual character* to which we must strive to give suitable answers and responses. Like John Bost and many others, we are convinced that all handicapped and mentally ill people—and even those who are heavily afflicted—should have access to the Gospels. Furthermore, we believe that they should be able to express their faith, in their own way, but perhaps thereby in a more authentic fashion. With complete respect for the beliefs and religious loyalties of each person, we seek to give both a personal pastoral help and a community-oriented spiritual and cultural life to those who ask for such things. Above all, for the last sixteen years we have developed a suitable catechism which draws heavily upon nonverbal methods of expression (one half of the people we take care of are not able to speak). We rely upon symbols, images, sounds, body movements, group experience. These catechisms, in which about two hundred patients take part, are certainly directed by a clergyman, but there is also a group of about twenty members of the staff, half of whom are Roman Catholics. The truly ecumenical spirit which animates this work owes a great deal both to the support of the Catholic hierarchy and to the Protestant churches of our region.

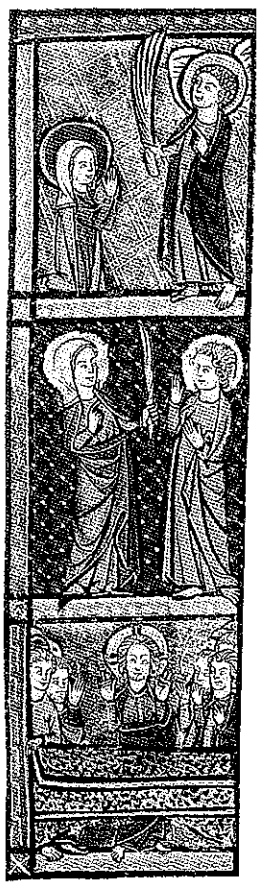
All this spiritual help is conceived by us as being a part of our institutional project. We do not see it as being yet another instrument of therapy but as a space of freedom which must be respected.

I would like to add that very often as well as being privileged recipients of the Gospels the people we take care of are also witnesses to it. More than one of the members of our staff have found or re-found their faith and their loyalty to their church thanks to the faith expressed by one of our patients or by the actions—which are often very moving—of service and solidarity between the patients themselves. How true are the words of D. Bonhoeffer: " God's way of showing his presence in the world lies in his weakness. "

In conclusion, we have an authentic need of the Church. By this I mean the Church in her universality and in her practical presence. This is because when confronted with people who are broken in body, or divided in spirit, or locked into their own weakness, or abandoned by the society of men, we do not feel that we have the right to add another factor of destruction or disorientation furnished by our denominational divisions. We need, above all else, to feel the presence of the Church—her solidarity, her prayer, the attention she pays to the youngest of our brothers and sisters, her visits paid to us and our visits paid to her. We want to be able to count on her so that she helps us never to become habituated to suffering and to avoid our treating it in banal fashion. Because the youngest of our brothers and sisters, whether they are rich or poor, intelligent or stupid, " handicapped " or " normal, " white or black, right-wing or left-wing, Protestant, Catholic, or Atheist, are always our brothers and sisters. This is especially true of the man or woman who suffers, whatever the name of his or her suffering might be.

The people our foundation takes care of belong to this category and for them there must be, and there will always be, hope.

Rev FREDERICK TRAUTMAN
Director General
of the John Bost Foundation
La Force, France



OSANNA BRUGNOLI

Handicapped People in Society

Personal experiences, even if they are special, full of significance, and of great exemplary value, cannot seek to be, or actually be, a prototype upon which can be grafted onto a project which must be imitated.

On the other hand, it is precisely in our culture of unrestrained competition that the sense of respect for the human person must be regenerated. This affirmation can be made without falling into pessimism in our analysis of society. This society does not work to the advantage of the handicapped, the elderly, those without power, or those who count for little. It benefits those who follow the cynical logic of climbing and advance and the de-educating attraction of success at any cost, of conformity to the ideology of power

But the need to set out the chief points of reference, whether personal or existential, necessarily involves a cultural testimony. These points of reference become, that is to say, practical ways of living inspired by something which we term values. They are life meanings, motivations, which characterize our actions.

These are premisses which I believe are essential so as not to give these actions the appearance of offering things which are taken for granted, derived from philosophies and ways of living which are preconstituted. On the one hand there is a risk of finding ourselves in schemata which have ways of seeing things which are nevertheless present in giving replies to our repeated and constant questions. It is that of sublimating our actions and imprinting our human experience—especially if afflicted by suffering—with regret, injustice, an interpretational key, or a heroic reply, where, notwithstanding everything, there is love, the faith that everything can be overcome in dynamic fashion, no-surrender, the giving of positive answers, the recognition of the capacity to trust oneself and trust other people. This is a strong and courageous response, which involves a freedom which is very far from being aesthetic and which comes to terms with the conditioning effects of nature, handicaps, upsets, and the highs and lows of our existence. In all this there can also be the admired consideration of a public opinion which values you and pays attention to you for a few seconds, in which the society of prosperity and success has not been able to hide suffering, trial, and pain—concerned as it is with attraction, arriving, and the presentation of everything as easy and happy.

There is also a person, by no means locked within nihilism, who proudly turns to God when the weight of desperation becomes unbearable and he asks: what have I done which is so bad to deserve all this pain? Pretentious friends and experts of the intimate and of society suggest hypotheses, detect causes and responsibilities in an attempt to console you. And you realize that they do not do it for

your benefit because they do not begin at the starting point of your " self " And then you begin to ask yourself a great many things, strengthened by your innocence, but also by your relative being, your precarious being, and you do not give up but keep playing until the end of the match. And you do not become paralysed asking yourself why God, destiny, or human wickedness have acted so severely towards you. And at a certain point you perceive that within you a courageous challenge is fighting by which you manage to discover that your being which seems particular is not different from those which are normal. It gives a response to life which is practical, which is functional in the role in which you find yourself, even if you are not able to understand why you are in that very state you are in.

It is not superfluous to make reference to the biblical Job who in his experience of evil, of physical decline, and of suffering, was defeated and tried to attribute to God the role of jailer and to affirm that the triumph of good was of less value than a euphemism. Such a temptation is always present, but here in this hall I want to present my experiences of daily life without the arms of hypotheses, queries, and consoling palliatives. I think that there is no reply to these existential questions. There is, rather, a challenge which leads me to live in a certain way. This is because the trauma and the overwhelming experience of a journey through the imponderable and an unexpected appointment with the unpredictable can only leave a deep mark in the psychic and physical life of an individual. And it compels you to think, to choose beyond being good and normality and acquired rights, beyond the canons of physical and psychic efficiency. It is what is called dependence, having need of certain things, of clear adaptations to a new type of life —something which is not considered in good terms by a so-called normal society.

I lay great stress on this analysis of a perverse cultural racism of modern man which is especially present in contemporary society. It is a culture which sees only winners and losers and against which Christianity opposes a different scale of values in favor of those who are weakest.

I know that the modern Western spirit is the heir of Nietzsche. It admires the winner, the rich man, the strong, the healthy, the beautiful. It is hedonistic and anti-ascetic. It is unable to distinguish between people who are good and people who are bad, people who are noble and people who are base, between the wise and the ignorant. It is, however, only too well able to distinguish between those who win and those who lose.

And it is at this point that I would like to express my challenge. It is not so much a response to the meaning of pain, or to the meaning of disability, but an attempt to lift the veil of hypocrisy that is present. I wish to show that so-called efficiency is not that which is now ascendant but that which sees the value of a man for what he is. And if I can offer an example, it is that of the human person who has reached maturity and who does not look down upon a child because he can not walk, who does not despise or marginalize old people who drag their feet along like people in rags.

The whole man is not the man we love or admire because he is efficient. He is above all else he who has preceded you and has attained a certain fulfillment and completeness. If you despise and marginalize the inadequacy of those who have not yet achieved efficiency or those who have lost it, you despise man and despise yourself.

The reality of the Mystical Body as described by St. Paul is very dear to me and gives me many grounds for hope. With effectiveness he illustrates the communion of love of believers and says that when a member, an organ of whatever kind, is sick, the whole body is affected. There are not, therefore, parts which are more important than others, and this is because all parts contribute towards ensuring or disturbing the health of the whole.

What is true for the human body does not seem to be true with regard to the social body. This is because there seems often to be a lack of that passion, love, and sharing which overcome all prejudices and every social obstacle. In the final analysis, I feel that I should live and feel what for me and many others love means—something which does not have the logic of contract-making or opportunism. Love, indeed, ignores social judgements and sees in the

loved person that which is unique and unmistakable. He is loved for what he is, and for his defects and his weaknesses as well. On the other hand I would not like to express these sentiments and fall into the trap of expressing values which are noble but a matter of words and ambiguous; not lived out, but merely displayed—a question of mere and hollow ostentation.

As a response to the torrent of words which are not borne out by facts, there is always personal experience. This can be something which relies upon serenity and a by no means easy balance—qualities which have always rejected living in terms of payment, gratifications, and a dignified sporting-personal-historical memory which is packaged and shown off for promotional reasons.

I truly believe that a brief perspective would consign me to memories—emphasis on a style of life which is made up of will, training, daily confrontation, and of giving me the knowledge of how to harness myself to this challenge to myself and to my life. The fact of being handicapped because of an accident and of thinking now in this way makes feel an ordinary person who rejects the label of being a " heroine, " of being an exceptional person. At a simpler level, I believe that my present day life—after the traumatic experience, the heavily present feeling of death, the endless incapacity of hospital, the image of hope of that pine tree that waved about outside my window—does not amount to a sort of adaptation to existence. I feel above all else that I should affirm that I was born, that I lived until the appearance of the accident, that in a certain sense I died and was born again. In this regard much help can be derived from the experience of the person who emigrates, of the refugee, who finds that he has to leave his homeland and go through the traumatic experience of an exodus, of an uprooting—a new life begins in the adopted land and a new adventure is set in motion.

Without giving license to narcissism, to memories and regrets, I think that the reality of a child who is by now grown up amounts to a great deal. A child, for a mother, represents an inalienable right to give, to love at any cost, beyond conformism to what is considered " normal, " beyond a conformism which does not welcome another person but continues to avoid him and to consider him precarious, as a citizen who belongs to another category, and whatever the case, as somebody who is without any doubt inferior.

In a complex society which is contradictory, violent, and often corrupt—such as ours most assuredly is—I am convinced, even if the idea seems utopian, that it is love which destroys the various forms of selfishness and guarantees an authentic respect for the human person.

In this place where I am now I think it is natural to remember the speech made by His Holiness the Pope on 3 April 1981 when he addressed the world handicapped games: " In Jesus Christ there is an important message for all disabled and handicapped people, " declared John Paul II, " for those that help them, and for the whole of society involved with them. Jesus Christ brought us a message which laid absolute stress upon the value of life and the human person. The human person comes from God and is called upon to live in communion with him. The same message can be read in the life itself of Jesus Christ—a life of love for the sick and for the suffering, and of service towards them. "

Dr. OSANNA BRUGNOLI
President of the Federation of the Handicapped, Rome

ELIAS WAKIM SAWMA

Living the Life of a Paraplegic

Whether or not it is traumatic, the condition of being a paraplegic is a very great trial for the healthy man. Suddenly immobilized by his affliction or slowly debilitated by increasing weakness, the paraplegic was—and still is—faced only with a future of immobility in a chair, humiliating forms of infirmity, and fatal complications.

Even with the very best therapeutic methods, he has witnessed the bright colors of his future fade away.

For fifteen years, faced with the presence of radicular and medullary injuries sustained during the so-called " Lebanese War, " I have developed and refined methods for effective re-education.

Ultimately, teaching these patients to live and survive and giving them the means to do so can be achieved only through precise information and with the help of all those who are called, from near or from afar, to play a role in this re-education.

Drawing upon an emphatically youthful, but also intensely and passionately felt experience of five years, I would like, during this paper of mine, to tell my story and dwell upon some of the most important problems I have come up against and had to deal with.

It was four o'clock in the afternoon on 20 December 1987. It was a Sunday, a week before the Christmas celebrations. I was going home, driving my car and accompanied by my parents.

All at once I heard the sound of gunfire. I then felt a cracking sound in my spine and felt that I had been broken in two. I then lost control of my lower limbs and, naturally enough, of the car.

A few seconds later blood was flowing out of my sides, I rapidly lost my strength, my sight went blurred, and I felt an intense thirst.

As I was taken to the nearest hospital in a state of shock I heard distant voices calling to me. I was surrounded by doctors and nurses who attempted rapid intensive care.

The clinical picture was dramatic: a high-velocity bullet had entered my left side and exited through my right side. The results were a state of shock and complete and flaccid L1 paraplegia with accompanying hematuria.

After the first forms of treatment had been administered, I was taken to a central hospital to be subject to an emergency operation.

The operation lasted six hours. I was then admitted to intensive care and kept under observation for five days.

My general condition progressively improved, but I felt electrical charges in my lower limbs and experienced painful hyperesthesia all over my body.

This was my first contact with " Pain. " It immobilized me completely. The smallest movement unleashed it in all its many aspects. There was traumatic pain caused by fragmentation which was localized where the spine had been broken; mechanical pain caused by the operation wounds in metameric bands —added to which were stabbing pains which came and went in waves, and less stereotypical pains —burning feelings, pins and needles, felt at the perineum as well. In addition to all this, there was a painful hyperesthesia which was provoked by the smallest touch.

This " pain " could only be alleviated, and then only for a short

while, by the strongest kinds of analgesics, such as morphine.

At the beginning, in hospital, when I sat in a chair I could resist for only thirty minutes.

At the outset, during my stay in hospital, I was still under the shock of the trauma I had undergone. This condition was characterized by a feeling of great physical fragility. I was also very afraid that a repetition of the traumatic episode, or of some other catastrophe or complication, could occur. This period of treatment, which was called " nursing, " in addition to having a purely curative purpose, also had the advantage of responding to an essentially physical anxiety with an equally physical drawing near—my traumatized body needed to be reassured, to find a certain coherence after this traumatic experience. An intensive context, both in terms of people and physical treatment, was indispensable at that time. Little by little, I acquired a clearer perception of my situation—I tried to understand that I had been injured; I looked at the film of what had happened; I listened to the people who had been there; I made many efforts to enable myself to regain a certain control over what I had gone through, and to find a way out of that intense period of anxiety.

My physical condition slowly became clearer: confined, or rather nailed to, my bed; incapable of movement or of feeling my lower limbs or of controlling my sphincters, I made a comparison between what I was experiencing within my own body and what I saw around me.

Forty days later I was in an intensive care unit. The state of affairs on my arrival was the following:

— complete D12-L1 paraplegia with complete sensorial lesion from the upper thigh downwards;

— complete motor damage to the inferior limbs with complete absence of reflexes and the lower abdominals;

— an absence of orthopaedic or cutaneous complications;

— with regards to the sphincters, the evacuation of the faeces was effected with a rubber tube; the removal of urine with periodic probes, the usual volume being 450 c.c.

I was surrounded by other paraplegics or tetraplegics whose spine had been damaged at one or other vertebra, and who were paralyzed at different levels of severity or for different time spans.

The wheelchairs, which had become a symbol of functional powerlessness, contributed to the perception of the image of the bodies of the other injured people which acted as a mirror of my own condition.

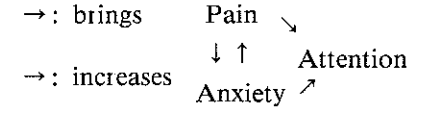
Each person tried as best he could to defend himself against this image: I will get better, I am sure about it, other people elsewhere have got better. Did I not feel this muscle, or my leg?

As time passed the successive assessments that were made enabled us to stay near to realities—the hope that there would be a complete recovery did not disappear but slowly came to occupy a secondary position. The discovery of my self-image as a paraplegic threw me into a reactional depressive state which was, however—and fortunately—of a transient character. This depression seemed to me to be useful, even if it was difficult to bear, as it was a way of treating myself—I seemed to be up against a " state of mourning " which was inevitable, mourning over an integrated personal image which no longer existed, mourning over an essential project, mourning over a certain kind of relationship with other people. All in all, so many " painful, but necessary losses ".

In these conditions, depression was lived through with a certain number of precautions—verbalization, anti-depression, and anti-anxiety medical help.

The pain took on another aspect. It was constant in the lower limbs and in the perineal region and took the form of a painful paraesthesia (pins and needles, stinging, itching) and the feeling of burning with a sensation of pressure, spasm, and heat. These last changed with the weather and when there was an infection, especially of a urinary character.

The " pain " tormented me. It increased the anxiety that was in me and meant that my attention was locked into a two-ringed circuit of positive feedback:



Closed in this ring, having lost all contact with the external world, and without any sense of passing time, I lived out my pain, moment after moment—analgesic positions, increased and higher heart beat and arterial tension, abundant sweating, especially from the hands, constant scratching of the hands, painful gesticulating and the frequent adoption of the " Omega " position, and a perturbed state of mind overlaid with great anxiety. And all this in expectation of, and leading up to, the next crisis. No kind of drug or electrical therapy could alleviate my condition.

Underlying everything was a permanent sense of pain—a sense of burning, a feeling of tearing in the tissues, twisting and turning, painful itching, and so forth. To this was added intense attacks of pain in the same areas, especially in the lower limbs, which were often similar to acute neuralgic pains of the trigeminus.

On top of this pain was the constant difficulty of sleeping: getting to sleep was arduous; I often woke up; I suffered from insomnia in the early hours. All this meant that I took a great deal of sleeping pills and similar forms of medication.

It was necessary, at whatever cost, to get out of that " hell "; otherwise it would have been the end. The only exit available was that of ignoring the pain, making sure that the people around me also ignored it, and making myself interested in these people. This was a kind of " functional lobotomy. "

I took an interest in the other paraplegics. I observed those who managed to get back their balance, both when they were seated and when they walked.

Knowing my injury and my capacities very well, I dedicated myself tenaciously to my re-education and strove to minimize my groans of pain. My sole aim was to reacquire perfect motor independence, both as regards a wheelchair and in walking.

Re-education included:

1) articular exercise with passive daily movement of all the damaged

articulations, and development of those muscles which had been left intact;

2) moving along a sloping path until an upright and independent position was reached;

3) re-education with regard to the upright independent position and getting into a wheelchair, balance in a sitting position—placing myself in a wheelchair especially represented a critical moment which was experienced as being condemned to remain paralysed;

4) re-education of the intact muscles—the key motor muscles and all the muscles of the spinal sulcrus, of the upper limbs, and of the scapular belt which is essential in the use of crutches for walking and independence when sitting down

After being a paraplegic for a short while, I wanted, above all else, to walk again without any artificial aids. If I had thought that walking was useless I would have given myself the impression that I had achieved only a partial re-education and would have felt that I was frustrated.

But it was an illusion to think that I would have been able to walk again without any effort. For this reason it was necessary to take part with commitment to attempts to strengthen the muscles of the upper limbs—quite apart from walking, these are essential to satisfactory independence in the sitting position.

Because the torso was normal and the lower limbs were entirely paralyzed, walking would have been possible only with Canadian crutches and femoral prostheses in four separate movements.

Re-education with regard to walking involves four stages: balancing on parallel bars, analytical walking between these bars, balancing on one's feet with crutches, walking forward with crutches, and, finally, standing on one's own feet without any aids.

In doing this I managed to achieve a satisfactory although not perfect level of balance despite my fear of falling, pains in my back and my lower limbs, and an old dorsal cyrtosis which disturbed the general balance of the spinal column.

Walking with mechanical and artificial aids was carried out in four stages but the efforts involved were modest—walking for half an hour at the most with the help of a kinesitherapist.

Two principal complications hindered my re-education: phlebitis in my left leg and acute pyelonephritis.

During my stay at the center I developed independence with a wheelchair to such a level of dexterity that I was able to obtain a maximum level of autonomy—I went backwards and forwards on a flat surface and could do slaloms without making the markers fall; I could deal with a rough surface; I could go up slopes, which at first were slight and later much steeper, and to do this used the " two wheels "; I was able to overcome such obstacles as a pavement or a step and in the end I was able to go up and down a stair with a few steps.

Furthermore, I developed abilities with regard to wheelchair sports: table tennis, volley ball, archery. I won a bronze medal at archery after only a month of training. To all this must be added swimming and the strengthening of the muscles of the lower limbs and the torso.

In addition to re-education, I took part in various kinds of activity—reading, games, cinema, writing, music—and engaged in the " recreation therapy " of the Anglo-Saxons. This consisted of preparing for social reintegration and the practical application of the progress achieved in my re-education, and attempts to secure a return to professional activity (the taking up again of my medical activity) and my social and family responsibilities.

The final result was that the intense pain became acceptable, even minimal, and I ended up by being able to live with it. I reduced my consumption of analgesics and strove to use only a minimal and essential dose.

" True anaesthesia "—that is to say, the absence of all sensation—is practically nonexistent in the case of the paraplegic. A whole host of unpleasant feelings are involved which a normal person could never bear and which would lead him to seek urgent help.

In this way pain drags the ignorance of paradoxes and contradictions in its wake!

We must mention here the most meaningful words of John Paul II's apostolic letter *Salvifici Doloris* —the value of suffering—which was sent to the clergy and lay faithful of the Catholic Church. In this letter the Holy Father remembers that " suffering has a special value in the eyes of the Church ". He grounds the true sense of suffering in the " supernatural, because it is rooted in the divine and profoundly human mystery of the redemption of the world, because man recognizes in it his humanity, dignity, and mission. Suffering is a part of the mystery of Man. "

We must draw near to that which is always true:

" As long as he suffers man can still continue on his journey of life " (Freud).

On returning home, I tried, on the one hand, to adapt my home—easy access, no steps, doors which were sufficiently wide, changes to the bathroom and my study; on the other, I strove to develop my motor independence, which became ever greater in the muscles of the upper limbs and the torso; I walked with crutches for an hour without stopping and without getting tired and with an ever better level of balance.

Presently, after five years, I can observe a distinct improvement in my physical condition—a clear diminution of pain, perfect motor independence in the wheelchair and in movement. I have also managed to achieve social, familial, and professional reintegration.

What does it matter if Beethoven was deaf; if Rembrandt was blind; if Damian was a leper; if Pasteur was paralyzed? The important thing is to give.....

To be a doctor, to treat and heal patients, is an honor. But to be a paraplegic doctor and treat others is an even greater honor. It is hard, but life must go on.....

Thank you, Lord! Through my very great trial I have been able to understand what paraplegia is; to understand what it is to be a " paraplegic. "

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ABDULLAH M. AL-GHANIM

The Disabled in the Middle East

As the foundation of the complement of natural resources that comprises any society human beings serve as contributing members according to their capabilities. The presence of a disability in an individual, whether physical or mental, should not be a hindrance to that person's enoying his or her full rights of humanity and being a source of human power for the community.

Care and provision of services for the handicapped indicate, to a great degree, the extent of civilization and respect for human rights that a society has attained. Adopting the twin goals of utilizing human resources and attending to the welfare of disabled individuals, each country in the world should take the initiative to prevent disability where possible, treat the disabled, and provide educational rehabilitation, training, and employment to help orient and integrate these people into society as fully as possible.

Islamic Society is mandated to appreciate, respect, support, and treat disabled well. That is because the Islam has stressed and specified the spiritual rights of the disabled as well as the rights to welfare, justice, and equal oportunities. In the Holy Koran and the prophet's sayings, the Muslim is urged to love, have mercy on, be kind to, and give charity to his brother Muslim (able and disabled alike).

Prophet Mohammad says, " Believers are just like one body in affection, mercy, and kindness. If one part complains, the other parts of the body will spend the right awake with fever ".

In compilance with those instructions of Islam and the ihnerited traditions, the Kindom of Saudi Arabia, under the leadership of the Custodian of the Two Holy Mosques, King Fahad Bin Abdul-Azeez, has been keen to extend the best facilities and most desirable services for the betterment of life for its disabled citizens; also, it has been dedicating scientific and technical research and social and medical care to them, as well as exchanging successful experiences in this field with advanced countries.

Achievements of the Kindgom of Saudi Arabia have continued ceaselessly to make the disabled today a productive force through different work locations and various occupations, such as carpentry, electricity, sewing, upholstery, painting, decoration, typewriting, computer and telephone operation, etc

Through these rehabilitation programs, it has been possibile to appoint a good number of male and female disabled persons to work in the government and private sectors, companies and various establishments. It is no more strange in our country to sec a blind telephone operator, or physically disabled typist or deaf person doing governmental or commercial work or to know a disabled person who has a special project of his own with financial support under the auspices of the central administration.

Furthermore, the Kingdom has endorsed all national and international efforts to provide the disabled with proper assistance in all fields of education, training, rehabilitation, and employment.

In particular, the Kingdom has been ceaselessly supporting all efforts that aim to improve the status of the disabled throughout the Middle East Region.

In order to convey a clear picture of the disability status in the Middle East, this paper is divided into four sections including: The Situation of Disability in the Middle East, Education, Rehabilitation, and Employment.

Situation of Disability in the Middle East

Unfortunately, the number of handicapped individuals in most of the countries in the Middle East has been increasing for two reasons:

1. The continuous wars that took or are taking place in several parts of the Middle East: Iraq-Iran War, Israel-Arab War, Lebanon Civil War, and Somalia Civil War.

2. The insufficient preventive health care services associated with poverty and illiteracy.

In any way event, a precise census of disabled people in the Middle East is not available. However, the total number of disabled individuals in the area is now roughly estimated to be around twenty million. That is equivalent to ten percent of the population of the Middle Eastern Countries as estimated by the World Health Organization.

In the Arab World, Our Regional Bureau of the Middle East Committee for the Blind conducted a survey to determine the status of disability in that part of the world.

We surveyed seventeen countries and got responses from ninety five percent of the samples studied. The results indicated that there were 103,603 disabled individuals, males

and females, who were receiving some sort of services.

They were subdivided into five categories:

	Individuals
1 visually impaired	2.320
2. hearing impaired	6.327
3 mentally retarded	5 878
4. physically disabled	21.173
5. others	47.903
TOTAL	103.601

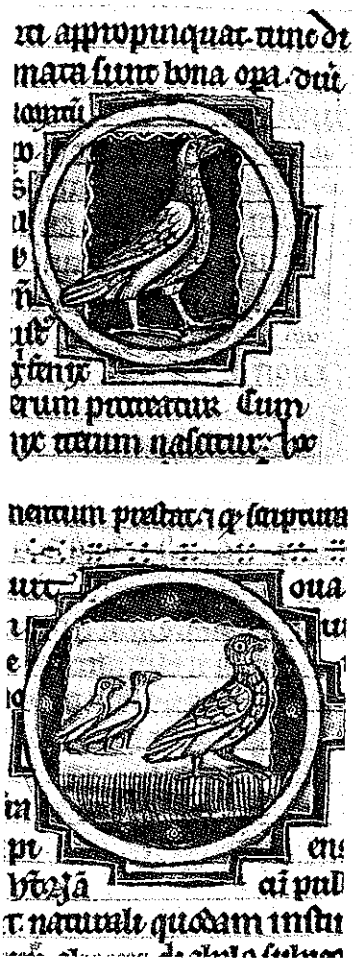
This number represents only less than one percent of the disabled population in the seventeen countries, estimated to be around thirteen million disabled persons, as indicated by the International Agencies.

These figures indicate the serious magnitude of this problem, which necessitates joint efforts and collective cooperation for the control and prevention of disability, as well as the need for the provision of intensive programs of action in the various fields of education, rehabilitation, and employment.

Now, in order to give you a clear picture the conditions and situation of the disabled in the Middle East, it will be helpful if we discuss the different services available for the disabled in the countries of the region, with focus on the main services in the field of education, rehabilitation, and employment.

It should be noted that, in general, these services are established mainly in the capital cities and other large urban centers. While provisions for the rural disabled seem to be rare, they do exist in some countries. Most disabled persons who benefit from the services have to leave their home areas in order to go to the very few centers that are available in the cities.

Even rural training centers are frequently located near the principal cities. Therefore, efforts a establishing centers in the rural areas should be encouraged.



Education

Education is of great importance for the disabled because, in its widest sense, it is a way to prepare them to participate fully in the social and economic life of the community, and to obtain as much of normal and independent life as possible. This preparation should start in the preschool years.

The handicapped people have proved that they are capable of being educated and integrated in to regular schools, if we give them the opportunity, to enable them get the whole benefit of regular education, with special help and special teaching aids.

Yet today, in the Middle Eastern countries, there are vast numbers of disabled children without any chance of access to education. Where they exist, even the residential schools are able to meet the educational needs of a very small percentage of disabled children in many countries. What will it take to change this situation? The main goal still must be to change negative attitudes towards handicapped people. This shift in attitudes is crucial if handicapped children are to be benefit from regular education.

In several countries, laws that have been enacted to require compulsory education include the disabled. However, compulsory education, is not, in fact, available for disabled children. Usually, it is determined by the accessability of schools, financial resources, and availability of educational equipment, qualified staff, and other necessary special services.

The Ministry of Social Welfare and Voluntary Organizations are responsible for education of disabled persons in most of the Middle Eastern countries, although we all agree it should be the responsibility of the Ministry for the education of nondisabled children, usually the Ministry of Education. Most of the countries do not have separate departments or sections for special education.

The residential school is still the primary method of educating disabled children in the region; while some programs aimed at integrated education have been launched, the lack of trained staff and difficulties with providing educational materials interfere with making such programs reality. Programs for training teachers of disabled children have been established in some countries. Other countries have attempted to solve this particular problem either by sending their

teachers abroad for specialized training or organizing short-term courses locally.

Nevertheless, the number of the professionals working with disabled is still limited. That is, there are only 8926 professionals in all centers for disabled in the seventeen countries that we surveyed. That means approximately 9 professionals for each 100 disabled. Also, the majority of those professionals were not trained in special education and related fields

Rehabilitation

The main objective of rehabilitation measures for the disabled should be to reduce the adverse implications of disability as much as possible, for the disabled person himself, for his family, and for community life. For this purpose, a rehabilitation program for the disabled should provide basic education mobility and orientation training, vocational and prefessional training leading to gainful employment, as well as, where applicable, access to higher education.

In most of the Middle East countries, rehabilitation services including mobility and daily living skills are not available to the majority of disabled people especially disabled women. The services in centers for disabled are not able to meet needs, and the quality of services is insufficient.

Placement and Employment Services

Placement of the disabled in a suitable kind of work is considered as the cornerstone in each rehabilitation program. In this connection, it may be said that rehabilitation could not be considered a tangible fact without placement and employment.

In spite of the great efforts exerted in many countries in the field, special job placement services for the disabled are still rare in developing countries. Efforts to find employment for the disabled are often made by the institutions where they were educated or trained. The majority of disabled people in these countries are not employed in income-yielding activities. The reasons for this are more or less thought to be: limited public awareness, poor rehabilitation of disabled people, and the absence of and legislative measures.

Conclusion

I hope this review has given you an idea of the conditions and situation of the disabled in Middle Eastern countries. We have seen that the existing services in the field of education, rehabilitation, and employment are insufficient to meet the needs of all disabled people.

Furthermore, it seems that the services are not likely to expand rapidly except possibly in a few countries, because of shortage of educational and training materials and of trained personnel. Then, what should be done in this regard? It is obvious that there is an urgent need for international action, based on the following priorities:

— The promotion of integrated education programs.

— Improvements in existing residential schools.

— Adequate provision of reading materials and educational aids.

— Programs for teacher training.

— The changing of attitudes towards disability.

— Broaden the educational opportunities for the disabled persons.

— Adequate vocational training

— Rehabilitation and training of disabled women.

— Establishment of efficient placement services in each Region.

— Drawing the attention of the governments of the region to including the disabled programs in their developmental plan of action.

— Appropriate legislation to ensure the right of the disabled to suitable employment, and to have legal protection against discrimination on the part of employers.

Priority—in particular—should be given to the ecouragement of rural rehabilitation projects, sheltered cooperative workshops, with a focus on community-based rehabilitation programs.

To achieve this, we need genuine pioneers who are fully engaged in the field. We also need unconventional leadership, creative staff, and other committed individuals intent on achieving the total integration of disabled persons.

Also, we need the support and expertise of the United Nations Agencies, as well as governmental and nongovernmental agencies to achieve our objectives.

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