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Proceedings of the XXIX International Conference

***Organised by
the Pontifical Council
for Health Care Workers***

The Person with Autism Spectrum Disorders: Animating Hope

20-21-22 November 2014

**New Synod Hall
Vatican City**

Editor-in-Chief
Archbishop Zygmunt Zimowski

Executive Editor
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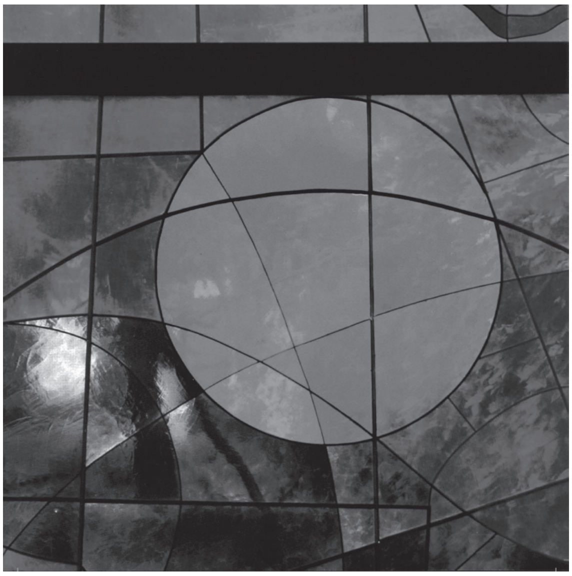

Editorial and Business Offices:
Pontifical Council for Health Care Workers (for Health Pastoral Care)
00120 Vatican City; Tel. 06.698.83138, 06.698.84720, 06.698.84799 - Fax: 06.698.83139
e-mail: **opersanit@hlthwork.va**
www.holyseeforhealth.net

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Speech of Greetings

H.E. MSGR.
ZYGMUNT ZIMOWSKI
President of the
Pontifical Council
for Health Care Workers,
the Holy See

Most Blessed Father,

It is with filial devotion and gratitude that we thank you for wanting to meet us at the end of the deliberations of our twenty-ninth international conference which addressed the subject ‘The Person with Autism Spectrum Disorders: Animating Hope’. This initiative was arranged around a number of sessions: the epidemiology and health-care policy of autism spectrum disorders; research, prevention and therapies; the early diagnosis and identification of autism spectrum disorders: and pharmacological, behavioural and innovative forms of treatment.

Lastly, we dedicated a great deal of time to addressing the subject of the theological and pastoral approach as well as the concrete activity of the Church in this sensitive and complex reality that involves the family in a completely special way.

During these three days of deliberations we were accompanied by your words that you spoke to Catholic medical doctors on 20 September 2013 ‘A widespread mentality of the useful, the “culture of waste” that today enslaves the hearts and minds of so many, comes at a very high cost: it asks for the elimination of human beings, especially of they are physically or socially weaker… This is why concern for human life in its totality has become in recent years a real priority for the church’s Magisterium, especially for the most defenceless, i.e. the disabled, the sick, the unborn, children, the elderly, those who lives are most defenceless.[1]

Your Holiness, that you agreed to meet us is for us a reason for profound joy which also finds expression in this climate of prayer and celebration that also finds an echo in these performances of song and music which are also intended to make people with autism spectrum disorders take part in expressing gratitude in being able to meet you on this unique and singular occasion.

In this context we will have an opportunity to be illumined and encouraged by you in our mission of care, ethics and pastoral care in favour of *Salus*, above all in order to animate Christian hope in the most difficult and precarious situations as well, in which human features, however troubled or marked they may be by suffering, can never in any way obscure the beauty and the dignity that are in impressed in every person by the Creator.

Lastly, as has by now become a tradition, I take the liberty of announcing in front of Your Holiness the subject that our Pontifical Council intends to address on the occasion of our next international conference which will be held, God willing, on 19-21 November 2015. In February 2015 we will celebrate the thirtieth anniversary of the existence and activity of our Pontifical Council and this event will coincide with the twentieth anniversary of the publication of the encyclical *Evangelium vitae*. It is for these reasons that the thirtieth international conference will embrace the subject ‘Serving the Culture of Life and Welcome: Twenty Years after *Evangelium vitae*’.

It is with filial obedience, Your Holiness, that we thus prepare ourselves to listen to your words and to receive your apostolic blessing which will accompany all those who are present, and in a special way those who experience the mystery of suffering and their families, supporting us in our commitment to being witnesses to faith in charity.

And as a sign of that hope which extends from the Risen Christ to the daily events of people with autism spectrum disorders, as well as their family relatives, researchers and various kinds of volunteers in this delicate clinical sector, we take the liberty of offering you a reproduction in gilded bronze of the ‘Christ of Hope’. This is a work that this Pontifical Council organised in order to being the comfort and solidarity itself of Jesus Christ to every context and to the side of every person who experiences the mystery of suffering and pain.

Thank you, Pope Francis! ■

Note

[1] Address of Holy Father Francis to participants in the meeting organised by the International Federation of Catholic Medical Associations).

Address of His Holiness Pope Francis

PAUL VI AUDIENCE HALL, SATURDAY, 22 NOVEMBER 2014

Dear Brothers and Sisters,
Thank you for your welcome!

I am happy to welcome you at the end of your 29th International Conference and I thank you for wanting to realize such a commendable and worthy initiative, dedicated to the complex issue of autism.

I warmly greet all of you who have come to take part in this meeting, which focused on prayer and testimony, together with people who are affected by autism spectrum disorders, their families and specialized associations.

Such disorders constitute a fragility that affects numerous children and, consequently, their families. They represent an area that directly appeals to the governments and institutions, without of course forgetting the responsibility of Christian communities.

Everyone should be committed to promoting acceptance, encounter and solidarity through concrete support and by encouraging renewed hope, thereby contributing to overcoming the isolation and, in many cases, the stigma to which people with autism spectrum disorders are also subjected, and often their families too.

This must not be an anonymous or impersonal accompaniment, but one of listening to the profound needs that arise from the depths of a pathology which, all too often, is difficult to diagnose, but – especially for the family – must be accepted without shame or withdrawal into solitude. It is a cross.

In the realm of assistance to people affected by autism spectrum disorders, it would be beneficial to create a regional network of support and services which are comprehensive and accessible. In addition to parents, these should also involve grandparents, friends, therapists, educators and pastoral workers. These figures can help families overcome the feelings, which can sometimes arise, of inadequacy, helplessness and frustration.

For this reason, I thank the families, parish groups and various associations represented here today and from whom we heard these moving and meaningful testimonies, for the work they carry out every day. I extend to all of them my personal gratitude and that of the whole Church.

Additionally, I would like to encourage the challenging work of academics and researchers, so that they may discover, as soon as possible, treatments and instruments of support and aid in order to heal and, above all, to prevent the onset of these disorders. All of this while paying due attention to patients' rights, their needs and their potential, always safeguarding the dignity of every person.

Dear brothers and sisters, I entrust you all to the protection of the Virgin Mary, and I thank you sincerely for your prayers. Now, all together, let us pray to the Blessed Virgin Mary for all health care workers, for the sick, and then receive the blessing. [Hail Mary... Blessing...]

Let us also now pray together for the soul of Cardinal Angelini, the Founder of this Council for health care, who began this service of the Church and whom the Lord called to himself last night. [Our Father... Hail Mary... *Gloria Patri... Requiem aeternam...*].

THURSDAY 20 NOVEMBER

OPENING ADDRESS

The Concern of Pope Francis for the Sick and the Suffering

**H.E. MSGR.
ZYGMUNT ZIMOWSKI**
*President of the
Pontifical Council
for Health Care Workers,
the Holy See*

I cordially greet the speakers, the chairmen and all those taking part in our international conference: thank you for your presence!

In beginning this meeting on the subject of people with autism spectrum disorders, I will dwell for a moment on the phrase that was placed in the title itself of this thirty-ninth international conference: ‘animating hope’.

This is truly the message that the Church, in her care and concern for the sick and the suffering, wants to bring to people with autism spectrum disorders and their families – a message of hope and joy amidst the difficulties, the limitations, the frustrations, and the sufferings caused by these disorders. Our Pope Francis is an authentic witness to this nearness of the Church to the sick and the suffering, a nearness that is expressed in his actions and his words. We will be able to see this nearness, which at times is moving, next Saturday in the Paul VI Hall. Pope Francis, indeed, will meet for the first time a universal dimension of the world of autism.

1. The Attitude of the Holy Father Towards the Sick

‘The Pope must serve everyone, especially the poor, the weak and the most vulnerable’, the Holy Father twittered to his millions of followers. He not only twittered this – he has also done this through his actions, approaches and words ever since the beginning of his pontificate, and he has always done it tirelessly.

One cannot deny that Pope Francis, during these almost two years of his pontificate, has displayed a very particular care for the suffering and the sick, and especially for sick children. Photographs of him while he embraces the sick and the suffering are by now legion in number: at times he is smiling, often with a tender and affectionate look that is full of compassion. I think that everyone remembers a photograph of the Pope during a general audience in St. Peter’s Square where he embraces a man who is gravely disfigured, comforting him and kissing him on the face, before blessing him with the sign of the cross. This photograph, which went round the world, does not need any comments, so intense is its testimony to Christian love. In this way, the Holy Father Francis shows us the pathway, the pathway to follow Christ and to serve him in the smallest, the elderly, the suffering and the sick. He bears witness from the deepest parts of his faith. When one sees him, one perceives that these kisses, these gestures of tenderness and compassion, are real, they come from his heart, and this moves everyone.

But our Pope is not satisfied with setting an example – he also teaches us. In his words we find a very profound teaching about suffering, illness, welcoming the sick, and the right Christian attitude to be adopted towards those who suffer. In addition, when addressing the suffering, he has spoken very vibrant and warm words that are full of charity, of faith and of hope, and words that are very strong and demanding in recognising the dignity and value of those who suffer. I would like to emphasise a few points about this subject.

2. The Culture of Waste and the Culture of Welcome

Pope Francis on innumerable occasions has spoken about the problem of contemporary culture which is not very welcoming towards those people who suffer. This is the ‘widespread mentality of the useful’ which the Pope calls the ‘culture of waste, that today enslaves the hearts and minds of so many’ and which ‘asks for the elimination of human beings, especially if they are physically or socially weaker’ (Address to those taking part in the meeting organised by the International Federation of Catholic Medical Associations, 20 September 2013).

The victims of this ‘culture of waste’ are ‘the weakest and frailest people’ (Meeting with disabled and sick children at the Istituto Serafico, Assisi, 4 October 2013). Because of this culture of waste, ‘concern for human life in its totality has become in recent years a real priority for the Church’s Magisterium, especially for the most defenceless; i.e., the disabled, the sick, the unborn, children, the elderly, those whose lives are most defenceless' (Address of the Holy Father Francis to those taking part in the meeting organised by the International Federation of Catholic Medical Associations, 20 September 2013).

In order to counter the completely negative influence of this culture of waste, the Pope invites us to engage in, and develop, a 'culture of welcome' which will assure to vulnerable and defenceless people a 'dignified life', even when there are 'grave difficulties': 'a sign of true human and Christian civilisation' (Meeting with the disabled and sick children of the Istituto Serafico, Assisi, 4 October 2013). Pope Francis lays stress on the concept of a 'culture of welcome'. This is something more than simply making room for people who are suffering, it is something more than offering them assistance and accompanying them as regards their needs: this is a matter of recognising in their persons value and riches.

A society is truly welcoming towards life, Pope Francis affirms, when it teaches people to see in a suffering person, beyond a simple appeal to assistance, above all a 'gift for the entire community', a 'presence that calls on solidarity and responsibility' (Message to those taking part in the general assembly of the Pontifical Academy for Life on the occasion of the twentieth anniversary of its institution,19 February 2014).

3. Words for Health-care Workers

The first words that the Pope offers to health-care workers do not relate to professionalism or the way in which sick people are accompanied. They concern the model that is the starting point, and to which one should always return, when one wants to be truly Christian. That model is Jesus, the Good Samaritan. 'Jesus is the way', Pope Francis tells us, and Jesus invites us to love other people 'as God has loved us', 'giving his life for his brothers and sisters'. Not only should we follow Jesus on the way of life, we should do even more: we must 'conform ourselves to Jesus, the Good Samaritan of all suffering people'.

The mission of health-care workers, therefore, involves drawing near to those people who suffer 'with love and tenderness', bringing 'the hope and the smile of God into the contradictions of the world' (Message for the thirteenth World Day of the Sick 2014).

On Saturday 15 November of this year, during his meeting with the Association of Italian Catholic Doctors, on the occasion of the seventeenth anniversary of its foundation and activities, he asked them to make a courageous choice, to the point of conscientious objection: 'Your mission as doctors places you in daily contact with so many forms of suffering. I encourage you to take them on as "Good Samaritans", caring in a special way for the elderly, the infirm and the disabled. Faithfulness to the Gospel of life and respect for life as a gift from God sometimes requires brave choices that go against the current, which in particular circumstances may become points of conscientious objection. This faithfulness brings with it many social consequences'.

4. Words Addressed to People who Suffer

We have thus finally come with Pope Francis to the heart of the question – to our brothers and sisters who suffer. Pope Francis has towards them an approach of listening and tenderness. In addition to actions, and this care and concern, he has words for them, certainly words of encouragement and tenderness but also words that are demanding, words that invite those who suffer to move out of a purely passive approach so as to become, in the places they find themselves, actors and the protagonists of hope.

The first words of the Pope for the suffering are to assure them that they are not alone: 'In Him every human pain, every anxiety, every suffering, was taken on our of love, out of a pure desire to be close with us, to be with us' (Address of the Holy Father Francis to those taking part in the plenary assembly of the Pontifical Council for Health Care Workers, 24 March 2014). Indeed, as Pope Francis explained in his message for the thirty-second World Day of the Sick of 2014, when Jesus 'mounted the cross, he destroyed the solitude of suffering and illuminated its darkness'.

The second words that the Pope has for the suffering is to remind them of the Word of God which shows that Jesus himself is present in the person of the suffering individual: 'The Church recognises in you, the sick, the special presence of the suffering Christ', and he went on: 'At the side of – and indeed within – our suffering, us the suffering of Christ; he bears its burden with us and he reveals its meaning' (Message for the World Day of the Sick, 24 March 2014).

And, lastly, the words addressed by Pope Francis to suffering people in 'moments of trial' are an invitation to follow Jesus who teaches us how to live pain. Jesus invites us in the first instance to have courage, to overcome our trials with patience (Santa Martha Chapel, 30 May 2014). But on its own courage is not enough to enable us to overcome suffering: we need hope, which comes from the light of Easter. Courage and hope together: 'hope, because in the plan of God's love even the night of pain yields to the light of Easter, and courage, which enables us to confront every hardship in his company, in union with him' (Message for the twenty-second World Day of the Sick, 2014).

'Jesus teaches us to live pain by accepting the realty of life with trust and hope, placing love for God and neighbour in suffering as well: it is love that transforms everything' (Homily, Santa Martha, 17 May 2014).

5. The Role of Suffering People in the Mission of the Church

In his care and concern for suffering people, Pope Francis is not satisfied with placing emphasis on their importance in the pastoral care of the Church but, in addition, he points out to us a specific pastoral approach which goes beyond assistance for the suffering and accompanying them. This is a matter not only of placing suffering people in a better way in the life of the Christian community but also of giving them an active place, of making them protagonists of the community.

'Dear brothers and sisters who are sick, do not look upon yourselves only as the subjects of solidarity and charity, but feel you are fully included in the life and mission of the Church. You have your own place, a specific role in the parish and in every sector of the Church' (To the pilgrims of UNITALSI, 9 November 2013, the Vatican).

With the same approach the Pope called on another group of sick people with the following strong words: 'United to the risen Christ you are active subjects of the work of salvation and evangelisation' (Audience for the Silent Workers of the Cross and the Centre of Volunteers of Suffering, 17 May 2014). With their sufferings, bearing them with patience and with joy in their hearts, the sick constitute, says Pope Francis, 'a precious treasure of the Church' (Address to the pilgrims of UNITALSI, 9 November 2013, the Vatican). One is dealing here with the 'charism' of suffering people, a charism that makes people who suffer with hope and peace in their hearts 'a gift for the Church' (Audience for the Silent Workers of the Cross and the Centre for the Volunteers of Suffering, 17 May 2014).

6. The Maternal Care of Mary

Pope Francis invites us to look upwards, towards Mary: he points to Mary for health-care workers as a model of maternal care, and for the pilgrims of UNITALSI on 9 November 2013 he invoked the miracle of the wedding feast of Cana when Our Lady said to the servants: 'Whatever he tells you to do, do it', as testimony of the care of our Heavenly Mother for all men.

And Pope Francis also addressed the sick and the suffering so as to invite them to turn to Mary, 'the mother of all the sick and suffering', as a 'road of suffering' (Message for the twenty-second World Day of the Sick, 2014). Mary 'knows, meets sufferings and always helps us in the most difficult moments' (Audience for the Silent Workers of the Cross and the Centre for the Volunteers of Suffering, 17 May 2014. Mary, Pope Francis adds, 'is always interceding and praying for us, especially at the hour of difficulty and weakness, at the hour of distress and confusion' (To the pilgrims of UNITALSI, 9 November 2013, the Vatican. UNITALSI: the National Union for the Transport of Sick People to Lourdes and International Sanctuaries).

'To her we can turn with confidence and filial devotion, certain that she will help us, support us and not abandon us. She is the mother of the crucified and risen Christ. She stands beside our crosses' (Message for the twenty-second World Day of the Sick, 2014).

7. Conclusion: the Message of the Grandmother of Pope Francis for her Grandchildren

Pope Francis thus points out to us with great force the way of Mary in accompanying the sick, and also points out this way to the sick themselves when they undergo trial and dismay. This convincing emphasis certainly has deep roots in the faith of the Pope.

This is therefore the moment to remember those magnificent words that were addressed by his grandmother to the young Jorge Mario Bergoglio, as to her other grandchildren. This is an authentic testament, for an entire life, and also for us today in this hall: 'Have long and happy lives. But if some day pain, illness or the loss of a loved one fills you with disconsolation, remember that a sigh in front of the Tabernacle, where there is the greatest and most august martyr, and a look at Mary, who was at the foot of the cross, can make a drop of balsam fall into the deepest and most painful wounds'. ■

Greetings of the Coordinator of the Network of the Ecumenical Patriarchate of Constantinople for Pastoral Care in Health

REV. DR. STAVROS K. KOFINAS
Coordinator of the Network of the Ecumenical Patriarchate of Constantinople for Pastoral Care in Health

Your Excellency Archbishop Zygmunt Zimowski, President of the Pontifical Council for Health Care Workers,

Honorable Ms. Beatrice Lorenzin, Minister of Health of the Republic of Italy,

Dr. Mary Healy Sedutto, Chairman of this, the twenty-ninth international conference of the Pontifical Council for Health Care Workers,

Honorable Dignitaries and Participants,

Bringing the greetings of His All-Holiness Ecumenical Patriarch Bartholomew, I express my gratitude for your invitation to participate in this significant international conference. The Pontifical Council is greatly respected by the Church of Constantinople and its work has proven to be a guiding light to all health-care professionals worldwide. We pray that your Council will be blessed and continue in the years to come to bear even more fruits of mercy and love.

Over the past years, the *Pontifical Council for Health Care Workers* and the *Network of the Ecumenical Patriarchate for Pastoral Care in Health* have developed a close working relationship based on sincere friendship and dialogue both at a theological and a practical level. The Ecumenical Patriarchate holds the firm belief that in a world where suffering is found in every aspect of man's earthly life, we must unite in our efforts to minister to the pain that is being experienced on a personal and social level throughout the world. If we are not united in Christ and guided by the Holy Spirit, we will not be able to hear the triumphant message which proclaims that our Savior's love has trampled down the powers that bring death and that the gates of His Kingdom have been opened for those that quest for eternal life.

This, your twenty-ninth international conference, which will concern itself with *Autism Spectrum Disorders*, is indeed a pioneering effort. For this condition brings dismay to so many people, both young and old. Caring for them often seems impossible. But autism places us before the challenge of finding ways to express love and accept love in a very special way, turning this difficult condition into a blessing. The Ecumenical Patriarchate awaits the conclusions of this international conference so that we, too, can benefit from your deliberations.

In a few days, Pope Francis of Rome will travel to Constantinople to meet with His All-Holiness Ecumenical Patriarch Bartholomew, joining in the celebration of the Ecumenical Throne on the Feast of St. Andrew, the Founder of the Church of Constantinople. In the light of this meeting, let us all pray that our two Churches will come even closer together in a bond of love and understanding. In expectation of the Pope's visit to the Ecumenical Throne, I would like here to assure you that our *Patriarchal Network* will continue forming a close bond with your *Pontifical Council* so that we, with one voice, can praise God who *"heals the broken heart and binds [our] fractures together*" (Ps. 146:3). ■

PROLUSION

Autism Spectrum Disorders in Childhood: a Challenge for Pastoral Care for Families

PROF. STEFANO VICARI
Director of the Child
Neuro-psychiatry Unit,
The Baby Jesus Hospital,
Rome, Italy

Autism Spectrum Disorders (ASD) are a pathology of the development of the brain which today constitutes an authentic social emergency – one child in every sixty-seven is diagnosed as having ASD. The new diagnostic manual for psychiatric disorders (*Diagnostic and Statistical Manual of Mental Disorder*, 5th edition, DSM-5) defines ASD as a disorder that manifests itself early and is characterised by a deficit of socio-relational and communicative capacities, in the presence of narrowed and stereotyped interests with a significant compromising of a person's performance in daily life. The word 'spectrum' suggests the idea of a complex pathology with an extremely heterogeneous clinical manifestation which moves along a continuum of symptoms that includes a broad range of phenotypes. The variables that principally determine the clinical condition of an autistic child are the cognitive level, the verbal abilities and the severity of the set of symptoms. The causes of autism have been amply explored and hitherto we know about numerous risk factors of both a genetic and environmental character which on their own, however, are neither necessary nor sufficient to cause the pathology. Some genetic conditions seem to be more connected with autism and numerous genes seem to be involved, while from an environmental point of view a risk factor in the genesis of ASD in the proband is the advanced age of the father.

The role that parents play in the complex phenomenology of ASD was debated for a long time and although this has not yet been completely clarified there exists strong agreement on the fact that there is a strong impact on their family, affective and social life. Scientific research has amply demonstrated that families that have children with autism spectrum disorders have higher levels of stress and a lower quality of life not only compared to families with children that have had a regular development but also compared to those families that have children with other pathologies, whether of a psychiatric character (mental disabilities, Down syndrome, etc.) or a physical one (cystic fibrosis). The answer to why it is specifically families with autistic children that have greater repercussions in their daily lives lies in the special characteristics of this disorder. Indeed, social and relational capacities constitute for a human being an essential aspect of life, channelling learning and the formation of the personality. Seneca, two thousand years ago, asserted that 'Man is a social animal and people are not made to live alone'. It is not surprising, therefore, that a compromising of such a central aspect has a strong impact on the parents.

In addition, autism is a pathology that emerges early on in an individual's life and alters the development of the individual for the whole of the course of his or her life. The lack of an identified and univocal cause and the absence of a cure further contribute to bringing about a complex, detailed and difficult daily state of affairs that is difficult both for the child and for the family. The parents find at the moment of the diagnosis that they have to restructure their expectations, hopes and prospects for the future, re-modulating not only the idea that they had built up as regards the growth of their child but also of the destiny of their family unit in economic, affective and social terms. Indeed, having a child with a pathology that has a strong social impact, as is the case with autism, often creates conditions of prejudice, stigma and social isolation that affect not only the child but also the whole family. The support network increasingly narrows around the grandparents or competent people such as therapists or educators, while the social dimension of friendship becomes difficult to maintain and manage. On the one hand, the parents of a child with ASD can have feelings of inadequacy, inefficacy, frustration or a sense of guilt in social situations. On the other hand, instead, friends and relatives can have feelings of irritation, difficulty, embarrassment or incomprehension when they are faced with the set of symptoms of the child. In a provocative sense one could say that autistic children create in a certain sense 'autistic families'.

However, the relationship between parents and autism has always been the subject of analysis, criticism, observation and theorisation and over the years its role has changed radically. About forty years ago Bruno Bettelheim, a psychologist and philosopher from Germany who subsequently moved to America, began a process of blaming the mother which is still talked about today. This author produced a theorisation which sees in the relationship between the mother and the child the roots of the genesis of autism. It was he who produced the definitions of the mother as an 'empty fortress' or a 'refrigerator-mother' in order to point to how the detachment and the purported coldness of the maternal figure has a causal role in the development of the syndrome of autism. This theory, in addition, led to the formulation of a consequent therapeutic treatment which saw the solution to the pathology as the separation of the child from the maternal figure, the so-called 'parentectomy'. The theory of Bettelheim dominated the scientific and rehabilitative panorama for many years, causing not only anxiety and a sense of guilt in the parents but also removing children from the possibility of improving their own skills and capacities because of an inadequate rehabilitation treatment. Starting from the 1980s these theories were steadily abandoned in favour of increasingly psycho-biological approaches which gave greater emphasis to components centred around the child rather than the child's relationship with the maternal figure such as, for example, neuropsychological and genetic components.

Although the shift of the focus from the mother-child dyad to the intrinsic characteristics of the child itself brought about, on the one hand, an absolving of the parent, on the other extreme it led from certain points of view to a process of hyper-attribution of responsibility in which the parent, who was no longer guilty, became the saviour of a child with autism. Indeed, some therapeutic approaches that are frequently advocated for children with ASD envisage the parents themselves being trained as workers who are able to administer the therapies to their own children and to take the place completely of external figures who are more suitable. For that matter, an absolute removal of responsibility offers obstacles to the progress of the child. To believe that the blame is to be attributed totally to fate, to destiny and to (mis)fortune brings about, in opposite fashion, a total exclusion of the possibility of being present in the growth of the child, completely delegating tasks to the therapy structures and delegitimating the parent's role of providing protection and care. Therefore at the present time the role of the parents seems to be moving along a subtle line where at the two extremes we encounter guilt, on the one hand, and salvation, on the other. However, as is often the case, the best and most effective strategies are the intermediate ones which allow mothers and fathers to be an active but not substitutive part of the therapeutic pathway of the child, accompanying him or her with adequate instruments that foster his or her development.

The task of carrying out an effective mediation between the two extremes of this line and promoting such intermediate and effective strategies to the pathology both in relation to the parents and in relation to the child belongs to the social-health-care institutions, to the therapeutic structures and to family associations. Indeed, these agencies should be placed within the process of the development of the child and accompany the patient and the family throughout the lives of the people involved, starting with an accurate and early diagnosis and then passing by way of a direction towards evidence-based therapies, that is to say those therapies whose efficacy has been scientifically demonstrated, to the point of achieving support during the adult life of the individual with autism. Unfortunately, the reality of care and treatment in Italy is very different and offers children and their families late diagnostic pathways, aspecific established therapies and no prospects as regards life after the age of eighteen.

Within this context the Baby Jesus Hospital seeks to provide a positive example to be imitated by promoting screening programmes as early as the first years of life in order to achieve an early diagnosis; by applying experimental protocols that can demonstrate their efficacy in a scientific way and not only an empirical way; and by cooperating with associations and foundations that are active in Italy in order to create a continuity between the paediatric age and the adult age. Every year more than six hundred children and adolescents are received in the hospital structures of the Baby Jesus Hospital both for a pathway involving the first diagnosis and for a follow-up and clinical tests. Utilising professionals of both the clinical and research fields who work in multi-disciplinary teams made up of specialist doctors, child neuropsychiatrists, psychologists and game therapists, it is possible to assure the use of protocols for diagnosis, assessment and treatment that are up-to-date and valuable. In particular, within the neuropsychiatry department we have engaged in inclusion of the parents in a programme of therapy mediated by the parents, that is to say a pathway of support for parenthood in relation to autistic children. Twenty-six children have taken part in therapy sessions where the therapy is mediated by the parents under the guidance of psychologists who are specialists in ASD. This takes place once a week with a total of twelve meetings. The results have demonstrated that compared to children who have not had such therapy these children have greater communicative and linguistic capacities. ■

Autism: the Relationship with Oneself in Suffering

PROF. CHRISTIAN FLAVIGNY
Child Psychiatrist,
the Department of Child
and Adolescent Psychiatry,
the Salpêtrière Hospital,
Paris, France

I would like to thank the Pontifical Council for Health Care Workers for giving me the opportunity to present you with the research that has been carried out on autism at the Salpêtrière Hospital in Paris[1] and the questions that derive from it in my view after forty years of activity as a hospital child psychiatrist.

In this paper I will concentrate on suffering – that of a child and his or her parents – but above all on the suffering of the bond between the parent and child, and of relationships that cannot flourish and deprive both the parents and the child of that sublime joy that the newly-born child expresses through his or her smiles, a joy that is experienced as the demonstration of being a son or a daughter that has taken place: he or she recognises us, we are his or her father and mother, they are my parents. In autism, instead, this demonstration is late in coming and seems to be refused. This moment of the first signs seems to flee and to be entrapped by autism.

Why? How? We will speak about this during the course of this international conference. But in this introduction I would like to centre my question around which teaching of child psychiatry should be adopted, certainly, but also and above all else around what human lesson we can draw from autism.

For this reason, I have to denounce, first of all, three excesses which in recent decades seem to me to have obstructed the clinical approach to autism.

1. The first in an insidious way related the problems of autism to an inefficiency on the part of the parents, to their purported inability to generate the first relational signs of their child.

It is certainly the case that no professional has ever directly formulated such an opinion.

But in not taking into account to a sufficient extent the intense feeling of guilt of the parents, professionals have not sought to alleviate that guilt, whereas this is the first condition for the therapeutic alliance that should exist between the parents and the health-care professional. It is not a matter, therefore, of erroneous expression but, rather, of a silence that should be criticised in this first excess, in an inopportune caricature of a practice take from psychoanalysis.

This is because if parents feel guilty, as for that matter frequently takes place in every difficulty or trial that afflicts their child, this does not mean that they are really guilty.

Thus the first excess is the omission of a suffering which should be alleviated.

2. The second excess limited, indeed still limits, autism to a neuro-physiological disorder with a genetic cause being attributed to it and focus placed on a picture of autism thought to be ‘pure’ that should be identified, a purported ‘purity of the syndrome’ which, it was supposed, placed investigation of the disorder on the pathway of genetic aetiology. I would like to observe that such a focus did not apply only to the field of autism. We have seen the same impasse in other fields of child psychiatry. I have described this inability to go beyond the hyperactivity of the child, assuming that there was a cerebral cause (which was called the *minimal brain dysfunction*) which was never identified but which decidedly remains the goal to be attained, even though it constantly escapes us.

This second excess has the fault of an excessive focus which limits research. I do not want here to go into the debate about the hereditary character of autism which is held to be high, albeit in a controversial way, in some studies on twins; nor into the debate about autism and mental retardation. All of this is the subject of useful debates. I would like, rather, to emphasise a problem which we may call epistemological. The studies on twins have a paradigmatic value only when they starting from the assumption that the cause that is looked for is genetic in character. Castore and Polluce, Romolo and Remo, although they are twins, are not similar if one takes into account the fact that they do not have the same name. Our research would be reductive if it excluded the relational dimension which has an important place in the study of autism, and of which the act of giving a name to a child is a privileged vector. The attribution of a name, indeed, confers on the child a place that is his or hers in the family lineage through a transmission starting with the eponyms chosen by the parents: on the one hand the godparents who open up a spiritual kinship and on the other the figure of the patron saint who is proposed as a model for the child, as takes place in all traditions, whether religious or lay in character. The act of giving a name to a child is thus a founding moment in welcoming the child into the world of humans, it outlines his or her prospects, holds up a destiny, and these certainly cannot be assessed like the studies carried out by geneticists but are, rather, an integral part of the clinical picture of autism, which involves a relational approach to difficulties and suffering.

Therefore this second excess concerns a focus induced by a single selective fact, which in this case is biological in nature.

3. The third excess reduces autism to a learning disorder and promotes educational programmes which at times are very binding and which almost become examples of maltreatment if one considers that there no cognitive acquisition is developed without there first being established an affective life. All learning, even that which is very elementary, is rooted in an affective experience which underlies it.

This is a principle of a position towards which we must first and foremost accompany an autistic child, where 'position' here means 'positive' and thus the possibility of the child hearing something like: 'I am here', 'I am positioning myself' – the first fact of the construction of identity which underlies the relationship with oneself ('I am positioning myself'). This involves a relational stability, an interior permanence which is steadily constructed, in the achievement of interior security, which, indeed, is an essential task of the clinical approach so that the child can feel a 'I am here' to begin with, as a 'I am here for them, they are waiting for me'. If it manages to become established, the principle of position allows the child to open himself or herself steadily to the possibility of denial, and thus of rejection, of distancing, with all the intense feelings that are involved in the fear of losing the relationship with his or her parents. If we reach this point we have gone beyond an essential stage.

This is a pre-condition for the opening up of a process of thought which is the key to learning: position and denial are its two columns and these are first and foremost affective and existential. Our interest should therefore centre around the positioning of the child in his or her relationship with himself or herself, starting with a stability, a permanence, which are the prerequisite so that he or she can first of all acquire language, being attentive to the fact that this is not only a matter of indicative words but also, and above all else, of expression. I often say that the most difficult thing is not having autistic children speak but having them acquire the music of words. Then there are the operational mechanisms: numeration is based upon a principle of position applied to the external world which assumes that it is first experienced and internalised by the child for himself or herself. This is the challenge that an autistic child has to address and why our mission is to help him or her.

Thus this third excess destroys a stage of the goal, which is nonetheless essential, of opening up the child to learning.

Autism is located at the dawn of the consciousness of man, it involves his various physical components – the sensorial, the emotional and the affective. It expresses the trial and the suffering when one or more components clash and do not manage to match. Our task as clinicians and researchers is to take into account the intricacy of these factors.

There is first and foremost a discordance between the various sensorial faculties, above all sight, hearing and the self-perception of the child's body and movements, which is clear at a clinical level and for that matter much cited in the testimonies provided by people who in the past suffered from autism. One is dealing here with a discordance between hypo- and hyper-sensitivity relating to touch, between hypersensitivity to contact and vestibular hyposensitivity, because the autistic child feels invaded by sensations and perceptions that he or she does not manage to filter and integrate immediately, as though the rays of the sun reached us through a hole in the ozone layer, bringing a folding in of relationships which, indeed, is a characteristic of autism.

We may observe, for that matter, that the recent American classification, DSM V, in 2013 recognised this sensorial dimension as characteristic of autism.

Our interest centres around sensorial inter-modality with care programmes that are at one and the same time corporeal and relational, after a sensorial-motional assessment in line with the spirit of the works of André Bullinger and employing an individualised approach because the disorders diverge significantly from one child to another. Our efforts are directed towards obtaining an integration of the identity of the child through the modulation of the sensorial perceptions that he or she receives so that he or she unifies them and appropriates them without being overwhelmed by anxiety. In many specific cases, emotional continence is completed by special programmes that envisage corporeal methods which are centred around the identification of the sensations of the body, hot-cold or dry-damp, the corporeal schema and movement, in an accompanied approach (psychomotional).

Another aspect of our strategy is related to learning, first and foremost of language, but with an approach centred around the child's capacity to express elementary emotions. This in particular is the objective of the Michelangelo European Programme which has been carried out in close cooperation with the team of Prof. Muratori in Pisa. Thanks to the use of two synchronised tablets, one of the child and the other of an adult, who can be a health-care worker but also one of the parents, this programme is designed to ensure that the child appropriates his or her own expression of emotions, can identify it and then express it. This, in line with the programmes of exchange and development carried out by French teams, has the aim of fostering this expression, supporting the relationship with the adult, fostering a dynamic if possible of pleasure which is shared when there is success, but also a dynamic of play, as well as the expressions in particular of relational imitation and differentiation between the child and the adult. Both the interest and the dynamic begun in the hospital can continue at home in the context of structured schooling.

This work associates the parents in treatment and care. They must be helped to identify the emotions of their child but also their own, but they should be associated without making them therapists of their children, and this so that they perform to the full their roles as parents. The question of the name given to the child is often an opening in this sense inasmuch as the name that is given to the child often has a history in the lineage of the family, albeit indirectly, and is related to the future, to the projects that the parents have been able to make and which have been painfully broken by autism, but which, however, should not be neglected. This allows a reception of the telling of their family history in order to understand the way in which the child is invited to enrol himself or herself in that history and is helped to that he or she can do this in a better way.

In definitive terms this is a developmental and multi-factor approach that seems to us to be propitious in autism. It draws upon the various perspectives, that of the tactile body and the motional through a psycho-motional approach; that of language with orthophonetic support: we know that autistic children encounter difficulty in expressing their emotions through prosody which we nevertheless know is essential in communication; and that of learning through the educational work of parental accompanying with the acceptance of the relationship between the parents and the child. The distribution of these approaches takes place according to the case of each child.

Autism directs us to the fragile, marvellous, delicate and at times intensely painful point of the transmission of the human – that process of grafting of the human that mobilises all of the components that are involved in the relationship between the child and his or her parents: functional neurobiological equipment, a sensorial integration that constructs the identity of perceptions, and an affective and relational connection. This grafting of the human provokes emotion, wonder but also trial, the trial testified to by autism through the suffering it creates. Autism incites us and our teams, with notable commitment and a great deal of humility, to ensure that the autistic child feels accepted in his or her dignity like every other child, in line with what he or she gives, because this applies because of the very fact that he or she gives, even though in the abyss of suffering. ■

Note

[1] Site: speapsl.aphp.fr

FIRST SESSION

AUTISM SPECTRUM DISORDERS: EPIDEMIOLOGY AND HEALTH-CARE POLICIES

1. The Historical and Epistemological Background to Autism Spectrum Disorders

PROF. FRANCESCA HAPPÉ
Professor of Cognitive Neuroscience,
Director and Head of Department
MRC Social, Genetic & Developmental Psychiatry Centre
Institute of Psychiatry, Psychology & Neuroscience
King's College London, United Kingdom

Autism has always been with us

Uta Frith has highlighted historical accounts of individuals with notable social and communication difficulties and rigid/repetitive behaviour of a type that would now warrant a diagnosis of autism spectrum disorder (ASD). Notable among these early cases are the 'Holy Fools' of the Eastern Church, dating back to the 6th century AD, including St Isadora of Egypt, Simeon of Emesa and St Basil of Moscow. Dewey and Dewey (cited in Frith, 1989) first suggested that the idiosyncratic, guileless, honest and isolated characteristics described in accounts of the Holy Fools might suggest that some of them had ASD; for example, many are said to have been insensitive to heat or cold, and to have lived as hermits with minimal contact with society. Frith (1989) has also pointed to evidence that some 'feral children' found living in the wild without human company, including the famous case of Victor the Wild boy of Aveyron (c. 1790), may have had ASD. A court-case from Scotland in the 18th century has been analysed by Frith and Houston concluding that the subject, Hugh Blair, was very likely autistic. The interested reader is also referred to Adam Feinstein's 'A History of Autism' (2010).

Autism is a recent diagnosis

The term "Autism" was first used to describe a group of socially impaired children by Leo Kanner, the director of Child Psychiatry at the Johns Hopkins Hospital, Baltimore. This word had been coined by Bleuler to refer to the disconnection from others seen in schizophrenia. Kanner's landmark 1943 paper, describing a case series of 11 children, introduced the term "Early Infantile Autism", with two defining features: 'Autistic aloneness' and 'Insistence on sameness'. Kanner wrote '*The outstanding, 'pathognomonic', fundamental disorder is in the children's inability to related themselves in the ordinary way to people and situations from the beginning of life…. There is from the start an extreme autistic aloneness that, whenever possible, disregards, ignores, shuts out anything that comes into the child from the outside.*'

At the same time, working in Vienna, the paediatrician Hans Asperger described a series of young people with somewhat better language and intelligence but similarly notable social-communication problems and rigid narrow interests, using the term 'autistic psychopathy' to label them. Asperger regarded the condition as akin to a personality trait, with good prognosis in the right circumstances. He describes a '*special clear-sightedness*', with '*in favourable cases… exceptional achievements*', and that despite '*helplessness in the matters of practical life*', '*work performance can be excellent, and with this comes social integration*'. At the time that Asperger was writing about these unusual young people, Austria and Germany were under the sway of Nazism; difference, let alone disability, was not tolerated and was wiped out wherever seen. In this context, it is poignant to read Asperger's plea, where he emphasises the possibility for good outcome (e.g. one young case grew up to become a Professor of Astronomy) given the right help: '*This knowledge determines our attitude towards complicated individuals of this and other types. It also gives us the right and the duty to speak out for these children with the whole force of our personality*' (from Uta Frith's 1991 translation).

Autism is not psychogenic

Kanner's original writings suggested an innate or inborn difference in children with autism, as do Asperger's papers. However, Kanner was later persuaded by psychogenic notions, based on his observation of traits of social/communication peculiarity in the parents of his young patients, and high SES/education in the families. Bruno Bettelheim directly proposed the psychogenic view of ASD, stating in his best-selling 1967 book *The Empty Fortress: 'The precipitating factor in infantile autism is the parent's wish that his child should not exist.'* The notion that cold or 'refrigerator parenting' could cause autism did immeasurable harm, inducing unnecessary and painful guilt, silencing the vital voices of parents as experts on their offspring, and misdirecting intervention efforts.

Subsequent research has provided no support for psychogenic views of ASD: there is no evidence that parenting is a cause. Instead, Kanner's observations regarding parental traits are now understood to reflect the shared traits in relatives of probands with ASD (the so called 'broader autism phenotype') due to genetic influences. His observations of high IQ/educational level/SES in families of those with ASD were almost certainly selection effects; only vocal and privileged families were able to access the famous doctor at the prestigious medical centre. Sadly, it is still the case today that underprivileged groups, including ethnic minorities, find it harder to receive an accurate diagnosis, and ASD is diagnosed later in underserved minority groups even in high-income countries such as the USA.

The overturning of the psychogenic view, and the recognition of ASD as a neurodevelopmental condition, relied on the courage and insight of many pioneers. Bernard Rimland, a psychologist and also the parent of a son with autism, collected together the evidence for a biological basis for ASD (e.g. strong association with epilepsy) in his 1964 book. Michael Rutter's 1977 twin study showed, for the first time, a clear genetic element. Lorna Wing, also both the parent of a daughter with ASD and a psychiatrist, carried out vital epidemiological work in 1979 that led to the concept of the 'triad of impairments, as well as introducing the notion of a 'spectrum' of manifestations. These important studies began half a century of biological research, which is well reviewed and summarised elsewhere (e.g., Jeste & Geschwind, 2014).

Autism is an evolving diagnostic concept

When Kanner's concept of 'infantile autism' first entered the formal diagnostic systems it was used interchangeably with 'childhood schizophrenia'. In the 1967 International Classification of Diseases (ICD)-8, 'Infantile autism' was listed under Schizophrenia, and in Diagnostic and Statistical Manual (DSM)-I and II the diagnostic entity was 'Childhood schizophrenia'. Even in the 1978 ICD-9, 'Autistic disorder' was categorised as a childhood psychosis. This categorisation changed in the 1980 DSM-III, in which 'Infantile autism' was placed under a new supra-category of 'Pervasive Developmental Disorder' (PDD). The PDD grouping persisted through the 1993 ICD-10 and 1994 DSM-IV, in which 'Autistic disorder' appeared alongside, for the first time, the new term 'Asperger disorder'. This latter category was introduced to refer to individuals with social and communication problems and rigid/repetitive behaviour in whom there was no significant language or intellectual delay.

The latest version of the diagnostic concept and criteria can be seen in the 2013 DSM-5 in which 'Autism Spectrum Disorder' includes the whole range of presentations, with specifiers to describe an individual's additional (language and intellectual) functioning and severity of social/communication and of rigid/repetitive symptoms. For a diagnosis of ASD to be given, an individual must show (or have shown) "Persistent deficits in social communication and social interaction across multiple contexts" and "Restricted, repetitive patterns of behavior, interests, or activities", beginning early in the developmental period and currently impairing functioning and adaptation.

Autism is not rare

Current estimates, from those countries where epidemiological studies have been performed, suggest that ASD affects approximately 1/100 children and adults. It is important to remember that most people with autism are children. According to a recent household survey in the UK, most adults on the autism spectrum have not received a formal diagnosis of ASD.

There has been much concern about an apparent rise in cases of ASD; is there an autism 'epidemic'? The USA Centre for Disease Control (CDC) reported that the autism prevalence rate in 2008 in 8-year-olds was 1 in 88, a 78% increase from the CDC estimate in 2004. However, more recent studies suggest a different picture. In the UK, information from the general practitioner (GP) research database from 2004-2010 (Taylor *et al.,* 2013), found a fivefold increase in the annual incidence rates of autism during the 1990s in the UK, but a steady rate since then. A systematic review and meta-analysis of all studies published to date (Baxter *et al.,* 2015) gives us perhaps the best current state of knowledge. Baxter *et al.* conclude that, as of 2010 there were an estimated 52 million cases of ASD worldwide, with 1 in 132 people affected. Importantly, from reviewing all studies up until that time, the authors conclude that there has been no change in rates of autism from 1990-2010. They also conclude that there is little regional variation in the data gathered to date, although it should be noted that epidemiological studies come from rather few and selected countries (Elsabbagh *et al*, 2012).

If the apparent rise in ASD has plateaued, at least in those countries with repeated epidemiological studies of acceptable quality, this has a number of important implications. It suggests that any environmental factors that have shown increased exposure over recent years are unlikely to have a major role in causing ASD. Instead, a plateau would suggest that the most likely reasons for the apparent rise include increased awareness, widening of diagnostic criteria, and diagnostic substitution (rates of 'intellectual disability' have gone down over the period when rates of ASD diagnosis were increasing; perhaps due to better service provision for ASD).

Autism is heterogeneous

A key feature of ASD, and a major obstacle to research, is the notable heterogeneity; as Lorna Wing liked to say 'When you've met one person with autism, you've met... one person with autism!' It is now generally agreed that many difference aetiologies underlie ASD in different cases. We have also suggested that, within any single individual with ASD there are several different underlying causes for different aspects of the ASD phenotype (see, e.g., Happé & Ronald, 2008). We have called this notion the 'Fractionable autism triad', and elsewhere present evidence that largely non-overlapping genetic factors influence the different symptoms of ASD (Happé *et al.*, 2006). This work, largely with population-based twin samples, is in keeping with family studies, which have shown that isolated subclinical traits of the 'broader autism phenotype' can be seen in relatives of those with ASD. For example, a child with autism may have a grandmother with rigid behaviour, a love of routine, unusual special interests and an excellent eye for detail (e.g. worked as a proof reader), but with good friendships and social skills. The same child may have an uncle who is described as a loner, finding social situations difficult, but without any notable rigid/repetitive behaviour. Thus the diagnostic features of ASD can be seen in isolation, even though the presence of the full triad (social, communication and RRBI) is required for a diagnosis of ASD. Understanding this is important for at least two reasons; first, it helps us understand heterogeneity in ASD and reconceptualise the spectrum as a multidimensional space in which social and communication difficulties vary independently of RRBI severity. Second, it motivates the study of isolated ASD-like social, communicative or RRBI difficulties in children not meeting full criteria.

Autism can be described at many levels

Elsewhere in this volume are contributions by experts on the genetics, neural and brain basis, and early behavioural manifestations of ASD. Autism can be described and understood at each of these levels: etiological, neural, behavioural. However, a vital level is needed to bridge from brain to behaviour; the level of the mind, as studied by experimental and cognitive psychology. Although it can be useful to know what brain regions are active when a person completes a certain task, it is usually not helpful to parents and teachers to have explanations of behaviour at the neural level. A parent might ask, "why does my son take everything he hears literally, so that idioms like 'she cried her eyes out', or everyday communication like 'we will be going swimming in the mini bus', confuse and upset him?" The response of the neuroscientist, "because his medial prefrontal cortex is not activated in the usual way", is not terribly helpful! Instead, such questions, and such puzzling behaviour, call for explanations at the cognitive level.

There are least three current cognitive theories that give insight into the patterns of behavioural strengths and difficulties of ASD, although none of them can explain all aspects of ASD, as predicted by the fractionated triad account (see Brunsdon & Happe, 2013 for review; see, Van de Cruys *et al.*, 2014 for an alternative view).

The social and communication deficits characteristic of ASD can be well understood as reflecting a lack of 'mentalising' or 'theory of mind' (see Baron-Cohen, Lombardo, Tager-Flusberg & Cohen, 2013, for further information). Theory of mind (ToM) refers to the everyday ability to attribute mental states to others in order to explain and understand their behaviour. We demonstrate our automatic and effortless ToM when we track what someone else mistakenly thinks. People with ASD fail simple tests of ToM, and more importantly show signs of 'mindblindness' in everyday life: lack of pretend play, failure to make or understand secrets or lies, and over-literal interpretation of communication (listening to the words, not inferring the speaker's intention, as in the examples above). This explanation of ASD moves beyond simple notions that people with autism don't care about others or are unsociable; instead it situates the difficulty in one specific social ability. Indeed, children with ASD are attached to their parents and do not differ in this respect from non-autistic children of the same developmental level. Many adults with ASD desperately want friends or to get married, but have difficulty making their behavioural approaches appropriate because they cannot intuit what the other person is thinking. Not being able to tell what someone is thinking, however, does not mean you do not care how they are feeling. Most people with ASD do have emotional empathy; when they can see that someone is in pain or distress, they feel for and with that person. So the ToM account helps to highlight other social processes that are *not* impaired in ASD.

The rigid and repetitive behaviour characteristic of ASD is not well explained by 'mindblindness', and instead a current theory is that this reflects impaired executive functions. Executive functions are the high-level abilities subserved by the frontal lobes, that allow for flexible problem-solving, especially in novel situations. They include a range of abilities such as planning ahead, monitoring your performance and changing track if necessary, inhibiting routine but inappropriate actions and generating new responses. Most people with ASD, like adults with later-acquired frontal lobe lesions, find it hard to switch from routine behaviours, generate new responses, and plan ahead (for more information, see e.g., Rosenthal *et al.*, 2013). Indeed it is these difficulties that often limit the independence and success of even highly intelligent adults with ASD. Executive dysfunction is not specific to ASD (it is also notable in, e.g., Attention Deficit/Hyperactivity Disorder), but it is an important part of the composite of cognitive characteristics that make up ASD.

The cognitive landscape of ASD includes not only valleys, but notable peaks; performance across IQ-subtests is typically uneven, and many people with ASD are strikingly good at something even when otherwise developmentally delayed. A child may be able to do complex jigsaw puzzles with the pieces turned picture-side down; another may remember the birthdays of everyone she has ever met; a third may instantly spot that an ornament in his room has been moved a fraction of an inch (sadly leading to a distressed outburst). In some cases, the ability stands in such marked contrast to the individual's other skills and to the skills of others, that it is termed a 'savant skill'. These arise in a rather circumscribed set of areas; music (e.g., absolute pitch, playing a piece after a single hearing), maths (e.g., calendrical calculation), art (e.g., amazingly detailed and accurate drawing), and memory (e.g., memorising the telephone directory).

The assets seen in ASD appear to reflect a superior 'eye for detail' (see for more information, Happé & Vital, 2008). Frith (1989) suggested this results from 'weak central coherence'; while neurotypical people look for meaning and the big picture, often losing the details, people with ASD don't draw information together in context and instead notice and remember details. There is now a great deal of research showing good performance by people with ASD on detail-focused tasks (reviewed by, e.g., Happé & Frith, 2006; Booth & Happé, 2008), and a range of theories that explain this in slightly different ways (see, for example, Mottron *et al.*, 2006). This work highlights that ASD should be seem not simply as a disorder, but as a different way of processing the world. Indeed, Temple Grandin, a brilliant professor of animal science, and writer about her autism (see http://www.templegrandin.com/), has suggested that it took people with ASD to invent the wheel, while the 'neurotypicals' were busy gossiping around the fire!

Autism requires us to respect difference

The spectrum of people receiving a diagnosis of ASD is very wide, and hence the diversity of experiences and views is also huge. It is important not to dismiss or neglect the needs and distress that many individuals and their families' experience. However, it is also the case that some parents will say, 'Autism is part of who my son is, and I wouldn't change him if I could', and many adults with ASD say, 'Don't try to cure me; my way of thinking and living is as valid as yours'. Indeed, much of what makes life difficult for people with ASD and their families is not the autism itself, but things that often accompany autism; anxiety, depression, sleep problems, epilepsy, language impairment, social exclusion and bullying. Many of these are remediable, and when improved, life with ASD can be substantially better.

Increasingly, the voices of people with ASD are being heard. There are active self-advocacy movements in many parts of the world, and many autobiographies and presentations by people courageous enough to describe their own experiences of autism. However, many groups are still neglected. We know scarcely anything about older adults with ASD (see, e.g., Happé & Charlton, 2012); what happens to people with ASD in old age? We also need to know much more about how ASD manifests in women and girls (Lai et al, 2015); is the 4:1 male: female ratio in part a reflection of poor recognition of the female presentation of ASD? Lastly, a fairer global perspective on ASD is desperately needed. While perhaps 80% of autism research and resources are concentrated on high-income countries, more than 80% of those with ASD are living in low-income settings, often without diagnosis or services.

As a society we are rightly judged by our treatment of the most vulnerable, and we have a duty to not only accept but also to champion the 'stranger' in our midst. A greater understanding of and respect for those with autism will increase our understanding of humanity and improve and enrich our society.

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2. Global and Coordinated Efforts to Manage Autism Spectrum Disorders

DR. SHEKHAR SAXENA
DR. CHIARA SERVILI
Department of Mental Health and Substance Abuse, World Health Organization, Geneva, Switzerland

"(…) je ne veux pas vivre dans une grande institution quand je devrai quitter mes parents. (…) Ça serait vraiment mon souhait le plus profound de pouvoir naviguer dans une grande souplesse entre ma chambre chez mes parents et mon chez-moi dans une petite structure. Pensez-vous que je pourrai avoir cette chance là? "

"(…) I don't want to live in a big institution once I have to leave my parents. This would really be my deepest wish to be able to navigate with great flexibility between my room at my parents' house and my own place in a small structure. Do you think that I could probably have this opportunity?" [Nassim, 16 years old]

" (…) I just keep thinking of the future of my child, how he is going to continue his life, and who will take care of him after his parents are gone. I know you would say his sisters and brothers could do that but if let's say one of the brothers agrees to take care of him nobody knows what will be the reaction of his wife. The problem exists here as in our country: they don't really support such kind of suffering.

I just can't sleep thinking about my child […] This is what each parent of an autistic child feels […] but we have all the hope and the big faith that things will be better." [Fand Alsarem, Saleh's Mom]

Persons with autism spectrum disorders and their families often face stigma and exclusion, inadequate access to health care and limited opportunities to live independent lives. Questions like the ones posed by Nassim and Fand were among those shared during an informal meeting held at WHO premises in Geneva on the occasion of the World Autism Awareness 2014.

Recent reviews estimate a global median prevalence of 62/10 000, that is one child in 160 has an autism spectrum disorder and subsequent disability. This estimate represents an average figure, and reported prevalence varies substantially across studies. Some well-controlled studies have, however, reported rates that are substantially higher.

In many parts of the world, including Africa, prevalence estimates are either unavailable or preliminary. With the exception of China, countries with a relatively large evidence base are high-income countries. A few studies have been conducted in middle-income countries and no prevalence estimate is available from any low-income country.

Neurodevelopmental impairments in communication, social interaction and cognition seriously hinder daily functioning of people with autism spectrum disorders (ASD) and severely impede their developmental, educational and social attainments. Autism spectrum disorders account for 0.3% of all disability-adjusted life years.

Persons with ASD are often exposed to human rights violations and stigma, and have limited opportunities to participate and contribute to the communities they belong to.

Autism spectrum disorders impose a huge emotional and economic burden on families. Caring for children with these disorders is demanding, especially in contexts where access to services and support are inadequate. Worldwide, most children with developmental disorders live in low resource settings. However, dedicated services are inversely proportional to a country's income, equating to a treatment gap of greater than 80% in low-income settings Moreover, most research on developmental disorders has been done in high-income countries.

Initial data from studies in the

United Kingdom of Great Britain and Northern Ireland and the United States of America indicate that estimated lifetime costs of caring for individuals with autism spectrum disorders lie between US$ 1.4 million and US$ 2.4 million per case according to the level of intellectual impairment. The reduction in family earnings due to the need to provide care for family members with autism spectrum disorders compounds the problem.

Autism was brought to the attention of Member States and the United Nations General Assembly in 2007. In January 2008, the General Assembly adopted resolution 62/139 which designated 2 April as World Autism Awareness Day. The subsequent observation of that Day has substantially increased international awareness on autism spectrum disorders.

On 12 December 2012, the General Assembly unanimously adopted a resolution entitled "Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders (ASD) developmental disorders (DD) and associated disabilities". It encourages Member States to enhance access to appropriate support services and equal opportunities for inclusion and participation in society for persons with autism spectrum disorders, developmental disorders, and associated disabilities. It recognizes that, in order to develop and implement feasible, effective and sustainable intervention programmes for addressing such disorders, an innovative, integrated approach would benefit from a focus inter alia on enhancing and increasing research expertise and service delivery. It also calls upon States to ensure inclusive education systems and to enable the learning of life and social development skills

In 2014 the World Health Assembly adopted a resolution on "Comprehensive and coordinated efforts for the management of ASD". This is a landmark achievement. The resolution requests WHO, governments and other partners to strengthen efforts to better meet the needs of persons with ASD. It demands advances in research and sharing of knowledge and technology for the diagnosis and treatment of ASD. The resolution also addresses Nassim's and Fand's concerns: it urges member States to implement plans for the technical, financial and human support of families and asks for a shift away from long-stay health facilities and a more comprehensive management of ASDs. Persons with ASD and their families will certainly play an important role in the future implementation of the resolution in countries.

WHO is collaborating with a network of experts, policy makers and civil society organizations to strengthen countries' capacities to address the needs of persons with ASD and other developmental disorders. During a consultation on ASD and other developmental disorders hosted by WHO in September 2013, international experts and advocates helped identify a number of key priority actions for WHO in collaboration with partners (http://www.who.int/mental_health/maternal-child/autism_report/en/).

They include the following:

– Enhance commitment of governments;

– Establish and sustain a global network of experts, UN agencies and civil society organizations; Generation of evidence to inform interventions and programmes for ASD and other developmental disorders;Assessment of needs and resources in countries and provide guidance on services;

– Provide guidance on the use of screening and diagnostic instruments;

– Make cost-effective training materials available for assessment and management of ASD and other DDs.

The latter is particularly important.

The lack of skilled human resources is recognized as a major barrier to increasing service provision for children with developmental disorders, preventing children from reaching their full potential. While comprehensive treatment models involving interdisciplinary teams of specialist providers have been shown to be effective, they require significant resources, which is problematic in low-resource settings given the limited availability of formal supports and interventions.

The identification of strategies for improving children's access to evidence-informed interventions by trained providers is listed among the top research priorities for improving the lives of individuals with mental illness worldwide, including those with developmental disorders. A systematic review conducted in 2013 of psychosocial interventions for children with developmental disorders delivered by non-specialist providers showed caregiver skills training programs (CSTP) to be an effective intervention for improving developmental, behavioral, and familial outcomes, which corroborates findings from other reviews.

WHO in its mhGAP evidence-based guidelines recommends that children being identified with developmental disorders at primary and secondary health care levels are offered parent skills training. In order to enable countries to follow this recommendation, WHO is developing, in consultation with experts and with support from Autism Speaks, a PST programme for caregivers of children with developmental disorders that will be freely available in the public domain and will be suitable for being delivered by non-specialists in low resource settings. We are pleased to provide additional information on this to anyone interested.

Lastly, I would like to end by emphasizing and prompting your feedback on a number of key issues that are critical for us to make a real change in the lives of persons with ASD and other developmental disorders:

– How can we continue to work with all stakeholders?

– How can we move from advocacy to capacity building?

– How can we make the effort truly global?

– How can we increase the resources within countries?

Let us not forget: "Care today, cure tomorrow". ■

3. Autism Spectrum Disorders: European Policies and Strategies

PROF. FABRIZIO OLEARI
Former President of the Higher Institute of Health Care, Italy

DR. MARIA LUISA SCATTONI
Brain Toxicology and Brain Endocrinology Section, the Department of Cell Biology and Neurosciences, Inter-departmental Autism Group, Higher Institute of Health Care, Italy

Autism spectrum disorders are a heterogeneous group of grave disorders of the development of the brain of an unknown aetiology. These disorders are characterised by a qualitative compromise in the field of social interaction and communication and repetitive and stereotypical models of behaviour, interests and activities. Recent data of the Centre for Disease Control which indicate a prevalence of 1/68 in the United States of America, and studies carried out in Europe which indicate a prevalence of 1/150, highlight how autism spectrum disorders have a relevant impact in terms of public health. On 30 May 2013 the executive committee of the World Health Organisation adopted, with the participation of over fifty countries, its resolution on ‘global and coordinated efforts for the management of autism spectrum disorders’ which defined priority actions to be engaged in at an international level to address autism spectrum disorders.

We are convinced that to address the complexity of a disorder of an autistic character a multidisciplinary approach is required. The question of early diagnosis, of helping and supporting families, or the endorsement of possible therapies, must be addressed through the implementation of appropriate health-care policies which cannot be separated from constant dialogue with the world of research and the world of the principal associations that represent the interests of patients and their families in Italy and the various countries of Europe. An international dimension to these subjects cannot be foregone in the identification of useful synergies in research in the aetiological, diagnostic and therapeutic fields, and in the formulation of positive shared activity in the European context to support strategies for care and treatment based upon the evidence.

For some years the ISS has engaged in research activity of both an experimental and clinical character in the field of autism spectrum disorders. A critical aspect in this sector is the need to actuate swift strategies which will allow an early indication of possible atypical elements in the development of a child and permit a maximum of competences. An early identification of precise indexes of risk would allow a monitoring of development and the placing of the child in a specific rehabilitation and surveillance programme capable of preventing or limiting the establishment and consolidation of those socio-communicative and behavioural anomalies that are typical of these disorders. To this end the ISS at the present time has been coordinating the Italian network for the early recognition of autism spectrum disorders, a network that was created with the IRCCS, the ASP, and Italian polyclinics and research centres with the aim of implementing an operational model of surveillance and assessment of the development of the brain in order to achieve an early identification of autism spectrum disorders in those parts of the population that are at risk. In addition, the ISS is involved in a formation project focused on instruments of surveillance and screening and the role that paediatricians, clinics and people who work in nursery schools play in the monitoring of the development of the brain and in a rapid reporting of atypical elements to specialist services.

In parallel the ISS has activated a national survey of services for the diagnosis and treatment of minors with pervasive development disorders (PDD), the first results of which will be presented within the framework of this international conference. This survey was carried out in the wake of the agreement that was signed in the year 2012 by the CUF: ’Guidelines for the Promotion and the Improvement of the Quality and Appropriateness of Care Initiatives in the Sector of Pervasive Development Disorders (PDD) with Especial Reference to Autism Spectrum Disorders’ where the ISS, the Ministry for Health and the regional and provincial governments were called to work together in order to promote initiatives involving the acquisition and diffusion of knowledge about these disorders. This survey was addressed to institutions involved in neuropsychiatry and rehabilitation in childhood and adolescence and was directed towards constructing a dynamic map of the services provided to people with autism spectrum disorders. Indeed it is of priority importance to develop a network of specialist health-care services involving diagnosis and treatment which are accessible and spread in a homogenous way throughout the regions of Italy, assuring a multi-professional and interdisciplinary approach that will allow the complexity and heterogeneousness of autism spectrum disorders in childhood and adolescence to be addressed, at the same time supporting families and processes of integration at the schooling and social levels for people of any age.

Only an alliance between the sectors of health-care, socio/health-care and education will enable us to respond in an effective way to the needs for care and treatment of disorders that emerge during childhood and adolescence. A fundamental priority is also the functional integration of mental health services for childhood and adolescence with those for adulthood.

A continuity in taking responsibility for such cases throughout a person's lifespan must constitute the model of reference because this allows a person with autism to conserve the abilities that have been acquired through measures of rehabilitation during his or her youth, thereby avoiding his or her regression and a waste of the resources that have been employed.

An early diagnosis of autism spectrum disorders (ASD), the identification of their causes and potential treatment through cooperation between national and international research centres, and the sharing of the best health-care policies and practices, are recognised by the World Health Organisation as the 'principal challenges to be addressed in the field of the management of ASD in order to increase health-care and social services and provide services for people with ASD and their families'. At a national and European level priority should be given to certain research subjects that are important and urgent, with consequent benefits that will go beyond each individual member State, addressing innovative questions and/or ones that are not yet covered, with a significant impact on public health policies.

The following research subjects appear to be crucial:

Estimates of the prevalence of ASD and consequent social and economic policies

A knowledge of such estimates of the prevalence of ASD at a national and European level is of vital importance for the planning of effective services and services that are correlated to people's ages. Only a few registers of autism spectrum disorders are currently underway in the world and only a limited number of epistemological studies of ASD exist that can be used to achieve a good assessment and suitable planning. We need shared protocols for the classification and assessment of people with autism spectrum disorders which are age specific. In addition, because of the fact that autism lasts throughout a person's lifetime, an assessment of the social and economic impact of this condition could provide essential information in supporting the development of health-care policies and addressing autism spectrum disorders in an effective way.

The early diagnosis of autism

At the present time in many European countries there is no coordination of general paediatricians, the personnel who work in nursery schools (age band: 6-36 months), and child neuropsychiatry units. This involves a delay at the age when a diagnosis of ASD is carried out (this is often done when the person involved is aged five or even later than this) and, as a consequence, a delay in acting. It is of fundamental importance to establish a multi-observational protocol and programmes of specific training for: 1) an early control of the emergence of behavioural anomalies in new-born children at high risk and in the population as a whole; and 2) to provide a provisional diagnosis at the age of eighteen months and a fixed diagnosis at the age of twenty-four months. This would allow the taking of early initiatives that can modify the natural life histories of individuals who have autism spectrum disorders.

Surveys of health-care and social services

There is an extreme need to gather detailed information on the organisation of services and the diagnosis and treatment of autism spectrum disorders during a person's entire lifespan. This information, together with calculations as to the prevalence of ASD, allows a better assessment of the health-care impact of autism spectrum disorders at a national level which in turn takes into account the gravity of autism spectrum disorders (the presence of co-morbidity and/or mental retardation) and the institutional and organisational characteristics of health-care systems and social care in each country.

The assessment of policies

Lastly, of essential importance is an assessment of the impact of existing educational, health-care and social policies to support people with autism spectrum disorders and their families in order to identify and promote effective and efficient policies. In particular, three major policies must be explored:

1) *Health-care policies*. These include clinical protocols for the identification and management of children, adolescents and adults with autism spectrum disorders, as well as protocols specifically directed towards ensuring a continuity and coordination of care and treatment from adolescence to adulthood. Data on previous treatment and on treatment that is underway should be gathered so as to assess adherence to existing guidelines and to develop and disseminate consensus documents.

2. *Policies to address special needs in the field of education*. Countries are notably different as regards the level of treatment of mental and learning disabilities (whether, physical, emotional or cognitive). A map of the educational systems of different countries could contribute to an identification of international good practices for the development and establishment of an effective and inclusive system of education and could also facilitate the integration into the workplace of people who have autism spectrum disorders.

3. *Social policies and policies to support occupational inclusion*. In some European countries public health policies exist for the prevention of ASD risk factors; there are social policies to provide support for people with autism spectrum disorders and their families through social or financial benefits, directed towards preventing or attenuating the impact of social malaise and social exclusion; and occupational policies are in place to facilitate employment and safety at work for people with autism spectrum disorders.

We hope that research groups throughout Europe are agreed on the need to coordinate their efforts and establish a research network that is characterised by a strong multi-disciplinary approach with the ultimate purpose of filling the knowledge gap and addressing the needs of people with autism spectrum disorders and their family relatives at a national and European level. ■

ROUND TABLE

Health Policy Strategies Adopted by the World Health Organisation in Favour of People with Autism Spectrum Disorders

1. Argentina

PROF. DANIELA A. ÁGUILA
Director of the Office
for Disability,
the Province of Santiago
del Estero,
Argentina

It is a great honour for me to speak at this twenty-ninth international conference on the subject: ‘The Person with Autism Spectrum Disorders: Animating Hope’. I am here as a representative of Argentina, my country, and I am speaking on behalf of the president of the National Commission for the Integration of Disabled people and the Federal Council for Disability of the Republic of Argentina, Dr. Silvia Bersanelli, who is also the president of the Committee for Disability of the Organisation of America States, OAS, (CEDDIS). Thus on her behalf and in my own personal capacity I will speak on ‘Autism Spectrum Disorders: Epidemiology and Health-Care Policies’ in Argentina and I will address this subject within the context of Latin America.

As we know autism spectrum disorders constitute one of the most complex conditions of development during early childhood and they have an influence more or less directly on people’s personal, familial, social and community lives.

In May 2014 the World Health Assembly approved the action plan on disability (a new world plan for global disability of the World Health Organisation 2014-2021) which seeks to improve the health and the quality of life of a billion people throughout the world who have disabilities; to increase their access to health care; to create new services and to strengthen those that already exist, and to introduce technologies into this field and improve the gathering of data and research.

The World Health Assembly exhorted the member States to include in their policies and programmes connected with the health of children and adolescents the needs of people afflicted by autism and by other disturbances of early development. This means increasing the capacities of health-care and social systems so that people can provide services to individuals with autism spectrum disorders and their families. It also encouraged all those directly involved in the relevant sectors, including autistic people and those with other disturbances of early development, those that take care of them and their family relatives, to take part in the development and the application of policies, laws and services.

Resolution A67/17 highlighted the need for the World Health Organisation (WHO) to strengthen the ability of countries to address the autism spectrum and disorders connected with it and to facilitate the mobilisation of resources, to work with networks dealing with autism, and to monitor the advances that are achieved.

This report argues that at an international level most of the people who are afflicted by ASD and their families receive insufficient attention from health-care systems and systems that provide social care.

In addition, it calculates that according to recent data the international prevalence of the problem is 62/10,000, and this means that one child in every 160 suffers from an autism spectrum disorder and the disability that derives from this. This calculation constitutes an average level because the prevalence that is observed varies considerably in the various studies that have been carried out. However, some well controlled studies have highlighted percentages that are substantially higher, such as that of the Centre for the Control and Prevention of Diseases in the United States of America which indicates an incidence of one child with autism in every 88 births.

It is evident that we are faced with a New Social Challenge

The increase in the prevalence of autism spectrum disorders has provoked great interest at the level of research.

With a certain justification it is thought most probable that the growth in the number of reported cases of a diagnosis of ASD is closely connected to: a greater awareness of autism in paediatricians and the members of families; a change in classifications; the broadening of the spectrum; and early identification and diagnosis.

When we consider my country, it is not extraneous to this reality. According to the census of 2010, the Republic of Argentina, which is in the extreme south of Latin America, has forty million inhabitants. Over twenty years ago, the movement of parents' associations gave an impulse to, and developed, initiatives to include people with autism. The civil society of families has been a pioneer throughout the world and this has been the case in Argentina as well.

This widespread presence has given rise to new organisations of civil society that are to be found throughout the country. Together with the national government and provincial governments they perform an important role in improving the quality of life of people with autism and that of their families as well.

It was civil society that gave an impulse to a project involving specific legislation in the field of autism in Argentina and to examples of such legislation that already existed in some Provinces. At the present time parliament is studying the passing of the *National Law for the Integral Protection of People with Autism Spectrum Disorders*. It has been blocked in the Chamber of Deputies of the nation and is waiting to be passed.

This Bill takes account of research into, teaching about, the early identification of, and the diagnosis and the treatment of, autism spectrum disorders. Its premiss is that there is a need for an integral and interdisciplinary approach. Furthermore, it encourages campaigns of sensitisation as regards ASD and the planning of the formation of human resources. It lays down the services that are needed for this integral and interdisciplinary approach and envisages an updating of these human resources whenever the advances of science so require this.

It also envisages the carrying out of epidemiological studies with the aim of learning about the prevalence of autism spectrum disorders in Argentina and the participation of the National Commission for the Integration of Disabled People in the formulation of any policy that is connected with autism.

This Bill is the outcome of arduous work carried out in agreement with the NGOs of the parents and relatives of people with autism spectrum disorders, together with various ministries of the national government and lawyers.

Epidemiology

Both in our country and in the Latin American region and in the rest of the world it is advisable to recognise that the existence of limited epidemiological studies and studies in the efficacy of the various forms of treatment has meant that we have not been able to expand and deepen research in order to understand who have a probability of being affected by autism, for example, or which could be the risk factors in exposing them to ASD.

Continuous questions still exist which mean that we cannot understand at a deep level why these disorders appear and how one can help to improve the lives of those individuals, families and communities that are afflicted by autism spectrum disorders.

Although fully aware of the continuous questions and uncertainties that we still have, we must nonetheless recognise that despite everything today much more is known about autism spectrum disorders.

For this reason, we must engage in initiatives that take into account the urgent need to continue with the research in order to look for answers. We must understand *more* in order to know *more* and attend even *more* to the needs of people with autism spectrum disorders and their families.

We must direct research towards *what* factors place children at risk and which systems of support can help. In this way we will be able to provide information in order to create programmes which are effective and can be rapidly implemented and which bring about better results so as to achieve the full inclusion of children with ASD in society.

One difficulty that presents itself is that of the training of professionals in the use of *diagnostic instruments* that then validate research that has been carried out. On the one hand, there are distances which make training difficult, and, on the other, there is the high cost of theoretical training and of the materials that are needed to use these instruments.

It is here that there arise opportunities for international cooperation to achieve that funding that is needed for research and thus the creation of national and international networks of researchers which can then be integrated into an international network involving the cooperation of researchers and/or one that operates in Latin America.

The Health-Care System

The health-care system in Argentina is made up, on the one hand, of the national government, and, on the other, of the Provincial governments with their own autonomous ministries.

In this area our country uses law n. 24901 which established a single system for basic services for people with disabilities who, indeed, receive 100% coverage.

At the same time in recent years initiatives have been promoted on a community basis and the task of a network for rehabilitation on a community basis has been explored.

For its part law n. 24901 has supported the work of teams and assures coverage for forms of treatment that have been agreed at an international level.

Instruction

Today in our country we are witnessing a process involving a transition from educational integration to educational inclusion and this has been paralleled by a growing commitment on the part of state schools to preparing the ground for such inclusion.

But '*schools are not islands. Schools will be that much more inclusive the more society is inclusive*', as Dr. Daniel Valdez, an Argentinian expert on autism, says. In this sense, the spread of information is of fundamental importance.

Special schools or specialised centres must be nexuses and sources as regards resources that foster the process of educational inclusion.

In all of the region we have a great opportunity to ensure that inclusive schools become a reality: we have positive experiences of inclusion in normal schools with instruments of support that emerged in the wake of the educational policies of the state which should necessarily be accompanied by a change in paradigm towards the social model. We have gone from seeing a deficit in terms of an individual to locating it within the contexts and limitations of learning and participation.

It is here that we encounter an opportunity to develop programmes designed to provide suitable instruments and support strategies based upon techniques with scientific support and constant updating as regards the various connected subjects and issues.

The advance of the region also involves proposals for the formation, qualification and updating of the professionals who work in this field.

With enormous pride, the Province that I represent, Santiago del Estero, thanks to help provided by the national state through the CONADIS, the National Commission for the Integration of People with Disabilities, and the institutions of civil society, created the *programme for the ongoing improvement of support for students with ASD (autism spectrum disorders).*

The aim of this programme is to offer qualifications *to train those responsible for training* for the support of students who have autism spectrum disorders. The recipients of this programme are professionals in the field of education who work in special state schools and who in their turn belong to support groups for educational inclusion in normal schools.

This programme received the prize for good practices in public policies awarded by the Federal Council for Disability in Argentina, and was also cited by the United Nations within the framework of the World Day for Awareness about Autism which takes place every 2 April.

Programmes such as those I have already mentioned thus offer concrete responses to a situation which should be taken into account since it is starting with the field of education that the need is most evident for training in supporting students with ASD. This is demonstrated by the fact that over 40% of students of the various faculties connected with this area are teachers in normal schools. The same is not the case with the professionals of psychology and/or psycho-pedagogy who have a different approach.

In particular, in Argentina there are signs of substantial progress being made as regards university training and this has been going on for over ten years, with the establishment of agreements with international universities and the promotion of exchanges and the generation of high-quality practices with a scientific foundation.

Lastly, it is important to point out that the technology at the service of instruction and training is a fundamental sign that enables us to shorten distances which at the outset appear to us to be unreachable but which in the end we see transformed from little dreams into great realities.

Starting with the context of Latin America I will now begin an analysis of the general situation of a number of countries.

Brazil

In Brazil, a country which has over 200 million inhabitants, one child in every 110 has autism. This means that there are 1.8 million people who have autism. Such are the figures as regards prevalence. There are high-quality research teams and in the legislative sphere law n. 12.464 is used. This law lays down that autism is a disorder of early development. In the field of research, various projects are underway and these are connected above all else with the field of genetics. Through these projects an attempt is being made to discover the causes of autism. The challenges in Brazil and throughout Latin America exist at the level of statistics and thus epidemiological studies have to be carried out that are reliable and sustainable.

With respect to forms of treatment, according to the federal law autism has to be treated at centres for psycho-social care for children. This is a public service with multidisciplinary and inter-sectorial teams which offers forms of treatment with different levels of intensity. At the present time in Brazil there are 136 centres of this kind.

Chile

Today in Chile there is greater awareness of the existence of autism spectrum disorders. This is due to the action of the government and to the social movement produced by families as well.

It was civil society, led by families, that directed attention to the important points as regards autism: clear and precise diagnoses, early treatment, inclusion at the level of schools, integration at the level of work, and a pensions and social insurance system. In this way it has been possible to visualise autism through the whole of the life cycle of a person without losing from sight autistic adults and elderly people.

As regards the field of legislation, Chile does not have specific legislation on autism.

According to the First National Study on Disability, 'Endisc 2004', 12.9% of the population in Chile has some disability, that is to say 2,068,072 people. On the basis of this figure, it is calculated that about 1% of disabled people have some degree of autism, that is to say 15,000 people.[1]

Peru

In the year 2014 the parliament of the Republic of Peru passed law n. 30150 which laid down that people with autism spectrum disorders have the right not to be discriminated against in all spheres of their lives.

The aim of this law is to create a legal framework designed to promote the early identification and diagnosis of ASD, rapid action, the protection of the person's health, integral instruction, professional training and the occupational and social integration of people with autism spectrum disorders.

Mexico

In Mexico it is calculated that one child in every hundred births has autism. This means that of the almost 2,600,600 births that were registered in the year 2011 by the National Institute For Statistics and Geography (Ungeri) about 25,000 children had autism spectrum disorders.

In 2010 the Secretariat for Health of Mexico drew up a Universal Catalogue of Health-Care Services (Causes) which contains a list of support services for ASD in first-level hospitals. This allowed in the year 2012 the creation of a Guide for the Clinical Practice, Diagnosis and Management of Autism Spectrum Disorders in which it is emphasised that *the early identification of children with autism spectrum disorders facilitates educational planning, planning in the field of family and care support, the management of stress in the family, and the achievement of suitable medical and psycho-educational care, and also avoids the worrying and anxiety-inducing trajectory which many parents follow before a diagnosis is achieved*.

We should observe that those parts of civil society in Mexico that dedicate themselves to this cause, like those of other countries which are cited above, work very hard to strengthen participation in an organised way.

On the other hand, it is necessary to work within a juridical framework that takes into account the rights of people with autism and harmonises public, social and private efforts to achieve the inclusion of people with ASD.

Conclusions

The rapid identification of people with autism spectrum disorders in Latin America constitutes a common denominator and development and thus it is necessary to engage in studies on the prevalence of ASD which are scientifically valid and to encourage research in the field of autism spectrum disorders.

According to the World Health Organisation, the responses to autism spectrum disorders must be based on transversal principles and criteria of universal access to, and the coverage of, services; on human rights; and on practices based on evidence, taking into account the totality of the life cycle; with a multi-sectorial approach and the development of the responsibilities of people afflicted by autism spectrum disorders and their family relatives.

Of fundamental importance is the improvement of the quality of existing practices in order to facilitate access to information and in this way to achieve valid contributions to studies on the prevalence of autism spectrum disorders.

We have to encourage the organisation of campaigns of dissemination addressed to the community in general in order to inform people and to promote awareness by the population of people with autism spectrum disorders and the importance of their inclusion in society.

We should also increase support services for the inclusion of boys and girls, adolescents, young people and adults who have autism, highlighting instruction, formation, support and reasonable initiatives, as well as their inclusion in the world of work, in order to foster their personal autonomy.

Latin American countries must strive to make accessible the adaptation and the validation of instruments for the early identification and diagnosis of ASD, promote the formation and/or training of professionals in this field, and create regional guidelines for research and the promotion of good practices.

In this field, the scientific world is invited to create instruments that allow the identification and the diagnosis of autism spectrum disorders at a global level, observing the validity and the utility of other diagnostic instruments of greater accessibility. On the other hand, a synergy should be created between researchers. We thus propose the formation of a *Network of Regional Cooperation in the field of autism spectrum disorders* in order to strengthen efforts to achieve these objectives within as short a period of time as possible.

It is important to emphasise that one should not lose sight of the *person* and his or her family. The direction of and support for the family is of fundamental importance in helping the family to face the challenge of living and coexisting with diversity.

The family and/or the tutors should be concerned to work for the present and the future of their children, looking for alternatives that will enable them to develop support services for the whole of their lives, thinking in particular of the ‘after us’ when the fathers and mothers of people with autism spectrum disorders will no longer be alive to look after them. ■

Note

[1] Source: www.senadis.gob.cl/sala_prensa/d/noticias/3774

2. Bangladesh

DR. SAIMA HOSSAIN
Chairman of the National Advisory Committee on Autism

Distinguished Guests, Fellow Panelists, Ladies and Gentlemen, good afternoon.

I would like to start by thanking the Pontifical Council for Health Care Workers, and particularly its President, Archbishop Zygmunt Zimowski, for organizing this year's international conference on a topic that affects millions of families around the world. And also for giving me this opportunity to showcase Bangladesh and share its journey towards greater tolerance, acceptance and compassion for those challenged with disabilities.

Autism spectrum disorders (ASD) are one of the most intriguing and challenging neurodevelopmental disorders facing people all over the world. ASD occurs in all cultures and across all socio-economic strata and occurs due to a combination of genetic and environmental factors. We know that there has been an alarming increase in the prevalence of autism, but we do not yet know the reason for this current public health crisis. Despite the fact that every 1 in 68 (1 in 54 boys) individuals are currently diagnosed with an autism spectrum disorder, and three international resolutions have been adopted by the member countries of the United Nations, we do not have a universally acceptable and implementable system for the assessment and treatment of individuals with ASD. One of the primary reasons for this lack of standardized support for families is that no two persons with autism are alike. Each individual with an autism spectrum disorder differs greatly in how they function and how the symptoms are presented. There are individuals who are challenged with comorbid conditions that prevent adequate physical mobility and there are many others with normal physical functioning. Some individuals with ASD may be non-verbal while others are extremely verbose. Persons with ASD also differ greatly in their level of intellectual functioning: although 50% may have below average intellectual functioning, there are many with exceptional skills and talents in areas that interest them.

In a developing country like Bangladesh, with a population of over 160 million, the challenge of autism is compounded by limited financial, professional and technical resources. However, even more than the lack of services, the greatest challenge has been that of social stigma and isolation. Stigma starts at home resulting in mothers being blamed for their child's unusual behaviors. Often mothers and their autistic child are isolated from the rest of the family and restricted to spending their days in a single room. Wives are abandoned and divorced mothers are left to raise their child as a single parent with little financial support. In rural areas, where resources are scarce, those with ASD are often taken to quacks and other untrained and unregulated 'village doctors' to cast out the bad spirits the family believes has possessed their loved ones. We often hear stories of families tying down the child with autism in their yard as the only means of keeping them safely at home.

In order to change existing negative attitudes, provide services and develop a sustainable approach to implementing services, we partnered with Autism Speaks and the WHO to launch the Global Autism Public Health Initiative and the Southeast Asian Autism Network. The high profile conference in Dhaka of July 25 2011 raised awareness about autism not only in Bangladesh but in the entire south Asian region. The resulting pledge of countries to work together, aptly named the 'Dhaka Declaration on Autism Spectrum Disorders', has been a catalyst for change and has significantly impacted not only autism but also how we address the needs of all persons with disabilities. Today, in Bangladesh, autism is not only a household name: families no longer associate shame and embarrassment with autism but acknowledge their family members' needs and are willing to seek appropriate professional help.

After our conference, and over a six-month period, during which we consulted with parents, experts and government officials, we completed a situation analysis of autism and other neuro-developmental disorders in Bangladesh. This process made us realize that in order to adequately support persons with autism of all age groups, we needed to develop our own multi-tiered model in order to address the needs within the community. We formed a National Steering Committee comprised of eight ministries: health, primary and secondary education, social welfare, local and rural development, women and child affairs, labor and employment, and finance (very recently three more ministries have voluntarily joined the committee), as well as a National Advisory and a Technical Guidance Committee made up of parents, experts and other stakeholders. Over a four-month process, a Strategic and Convergent Action Plan on Autism and other Neuro-developmental Disabilities (SCAPAND) was formulated by the steering committee. In 2013 SCAPAND was incorporated into the five-year National Development Plan.

Every year on April 2 we participate in the annual 'Light it up Blue Campaign' and celebrate the World Autism Awareness Day with street rallies, art exhibitions, essay and art competitions, and a cultural show performed by persons with autism which is attended by the honorable Prime Minister and broadcast nationally. I should also mention here that every year Prime Minister Sheikh Hasina selects paintings done by persons with autism for her official greeting cards. Along with national recognition, these artists also receive financial remuneration for their artwork.

Since 2011, in collaboration with local and international institutions, we have conducted numerous sensitization training courses for health-care workers, doctors, teachers, social workers and other community-based service providers. Approximately 6,000 community clinic workers, 300 pediatric consultants, 400 newly recruited secondary teachers, 100 teacher trainers, 65 master trainers for social workers and 40 physical therapists have been trained in the field of ASD. Disability information has been included in medical school curricula, teacher training manuals and also incorporated into the social studies curriculum starting at grade 1. Through parent-based organizations, families are provided with scientifically-based information and training so that they can be well informed advocates for their loved ones. We have conducted two national surveys to gather data on the prevalence of disability in Bangladesh. The Ministry of Social Welfare conducted a door-to-door national survey on disability and the Ministry of Health and Family Welfare completed a pilot project in which community health workers screened nearly 7,000 children from birth to age nine for a developmental disorder across seven districts of Bangladesh. Last December we adopted a new disability policy and founded a National Trust for the Protection of Persons with Neuro-developmental Disorders.

Despite all this progress in enhancing social acceptance for persons with autism we are still faced with enormous challenges. There is a significant dearth of trained professionals, we lack standardization in the training of our expert service providers, and centers where services can be provided are few in number and limited to urban settings. We do not have a standardized procedure for diagnostic assessment and few trained professionals are there to provide therapeutic interventions at the early stages of development. In addition, for the social and economic inclusion of persons with ASD, we not only have to ensure early identification and evidence-based intervention, we also need appropriate educational and employment training programs. Since these challenges are common to many countries, this September we launched the Global Initiative on Autism (GIA) in order to enable greater collaboration and coordination between institutions and organizations, both governmental and non-governmental. Through effective international partnerships I hope that a structured and well planned action plan will emerge of cost-effective and sustainable services and programs that can be implemented in low-resource settings. The primary objectives of the Global Initiative on Autism (GIA) are:

1. The promotion of rights to inclusive development.
2. Addressing the needs of individuals throughout their lifespans utilizing multi-sectoral planning and action.
3. Sharing sustainable strategies of service delivery systems through public-private partnerships.
4. Raising awareness, ending discriminatory practices, and enhancing greater participation and inclusion within communities.
5. Promoting greater access to affordable health, education, employment and social services.
6. Empowering individuals and including them in the decision-making process.

Conferences such these are a clear indication that in order to enable our most vulnerable citizens – those with autism spectrum disorders – become socially and economically productive we need a coordinated and structured global response. By working together we can hope to build a more compassionate and inclusive global community that includes everyone regardless of their abilities.

In the words of Pope Francis: 'Human rights are violated not only by terrorism, repression or assassination, but also by unfair economic structures that create huge inequalities'. I therefore commend the Catholic Church and the Pontifical Council for Health Workers for prioritizing neuro-developmental disorders and reaching out to families in need. I would like to assure them of my and my country's utmost support in their endeavors to end this inequality. ■

3. Malaysia

HON. DR. DATUK SERI
S. SUBRAMANIAM
Minister of Health,
Malaysia

Autism is one condition that has not yet been given due attention by various countries. This has created ripples of interest amongst various parents and non-governmental organisations in seeking rights to access to, and the availability of, appropriate and specialised services for children and persons with autism spectrum disorders (ASD). Despite their extensive presence, many governments have not been able to provide enabling environments for people with ASD in order to develop their maximum potential.

The WHO in 2013 estimated that the prevalence of autism was 6.2 per 1,000, or equivalent to one child in 160 with an autism spectrum disorder. Many studies carried out have revealed, however, a varying prevalence. *The Lancet* in 2006 showed that in children of

8-10 years there is a prevalence of 11.6 per 1,000, while South Korea in 2011 showed a higher prevalence of 26 per 1,000 in 7 to 12 year-old children.

In the United States, the incidence in children aged 8 in the year 2010 showed a range from as low as 5.7 per 1,000 in Alabama to as high as 22 per 1,000 in New Jersey.

Closer to home, a prevalence study in 2005 in Malaysia on toddlers (18 months to 3 years), which is a much younger population than many of the other studies, showed a rate of 1.6 per 1,000 children.

Despite the apathy, today science and policies have proliferated, creating a deluge of information for families to sieve through. Families play a pivotal role in understanding the condition of ASD, accessing holistic, care and participating rigorously in help and treatment during the lifespan of individuals with ASD, often with perseverance and self-determination notwithstanding the countless trials, errors and disappointments.

The management of ASD requires a multidisciplinary team and involves multiple sectors. Generally, the health sector is responsible for early detection through early childhood screening and the carrying out of the diagnosis. This requires trained medical personnel and validated tools to be employed systematically throughout the health system. Equally important, the next step of providing appropriate intervention mandates the availability of various categories of trained human resources, namely educationists, psychologists, audiologists, speech therapists, occupational therapists and counsellors, in managing ASD.

With so many different autism treatments available, in the absence of structured appropriate interventions it can be tough for parents and families to figure out which approach is right for their child. Making things more complicated, they may be confronted with many conflicting recommendations from friends and doctors. Each parent needs to take heed that when putting together an autism treatment plan for their child: there is no single treatment that will work for everyone. Each person with ASD is unique, with different strengths and weaknesses. It is important to recognise these challenges and to allow for maximising potential within diversity.

Hence, central to all these interventions family and community support must be well sourced with useful information necessary to assist and reduce the burden shouldered by parents and families. The bigger the network of support, the sooner individuals with ASD can be well integrated into the fabric of society.

During the last World Health Assembly, I was struck by a comment from a patient advocate who made this appealed: “don’t try to make us normal by your definition; accept us for what we are and maximise our potential by creating the environment”. He also expressed his fears that early intervention would result in behaviour modification to turn autistics into “normal” people. He also asked: “the steps to introducing prenatal genetic testing and abortion, can this lead to eroding the rights of people with disabilities”?

We must recognise the fact that we are not just faced with a medical condition: what we are dealing with is also a mesh of issues relating to the social, psychological and ethical domains of individuals with ASD that have to be critically addressed and be acceptable to the local society. In the management of ASD the aims should thus be functionality, social recognition and independence.

Taking cognisance of the issues that had been deliberated, several recommendations were made during the sixty-seventh World Health Assembly in April 2014 for countries to take certain initiatives. These included: strengthening the infrastructure for a comprehensive management of autism; addressing the disparities in access to services for persons with autism; conducting specific research on the public health and service delivery aspects; strategizing relevant policies, legislation and multisectoral plans; and conducting regular training for all professionals working in the assessment and provision of services.

Sharing with you what we have done in Malaysia, autism has been given a high profile through the leadership of the wife of the Prime Minister. We initiated and hosted an International Seminar on Autism on 22-23 April 2014 and we are now planning a Centre for Autism under the Prime Minister’s Department that will focus on training and service in excellence and research.

Policies and legislation have recently been constructed in order to support and strengthen the plans for the management of autism. In the health sector, the autism programme has been integrated into the Health Care for Persons with Disabilities (PWD) 2011-2020 Plan of Action. At the primary care level, the main activities include screening for early detection and intervention, while the secondary care level looks into diagnosis and the management of complications.

In Malaysia we are currently using the M-CHAT (Modified Checklist for Autism in Toddlers) as a screening tool for children of 18 months and 3 years of age. This checklist has been incorporated into the home-based child-health record provided to every newborn child, with an average of 300,000 children per year since 2008. However, acknowledging that new screening tools are being developed that are more sensitive and specific, they will be incorporated once there is evidence and proof that they are a better option.

Once a diagnosis is made in the primary care clinics by our family medical specialist they will offer a care plan. The children are followed up by nurses and therapists. A series of six manuals on the management of children with disabilities has been developed and they have been made available online for ease of reference.

However, we have made less progress in developing older adolescent/adult autism services. Taking a long-term view, the considerable investment we are making in children’s services now should lead to future dividends, given that more robust provision during the early years of development is known to ameliorate the more severe impact of disability in later years.

With regard to employment, most countries today do recognise the right of persons with disabilities to work on an equal basis with others. Hence there should be adequate time given to persons with ASD to adjust to the changes imposed on them.

Employment and employability are issues which require various government departments to work together to support people with disabilities to gain and retain employment. This work must concede that those who face greater barriers in accessing work will need more intensive and focussed support, increasing opportunities for people with disabilities to attain skills and qualifications through access to appropriate training and lifelong learning opportunities.

While many plans and strategies have been shared across countries to achieve ensuring holistic services, the challenges of a lack of appropriate tools and supportive equipment, trained manpower, and financial and technical resources, remain as major challenges. The need for a national health information and surveillance system, and an ASD database, is vital in monitoring and achieving strategic development. In addition, more research needs to be carried out to understand this condition so as to develop better interventions and to identify and address disparities in access to services for persons with ASD.

In conclusion, many more efforts need to be made. Hence let us work together to ensure that the services rendered and provided by government departments and non-government institutions for people with autism, their families and carers, establish platforms and tailor them to meet the changing needs of people with autism over the course of their lifetimes by:

– Promoting awareness and better understanding of the challenges faced by people with autism.

– Supporting people with autism, their families and carers to become well informed and making available the various services they need.

– Encouraging social inclusion of people with autism and working to address discrimination/stigmatisation. ■

4. Italy

PROF. ROMANO MARABELLI
General Secretary
of the Ministry of Health,
Italy

The protection of mental health is a subject of priority attention in the planning of health-care and social policies in all industrialised countries.

In the European region of the WHO and at the level of the European Union all the member States have signed commitments at the level of planning which identify priorities and initiatives for the ten-year period 2005-2015 (the Helsinki Declaration and Action Plan, the Green Paper and the European Pact on Mental Health and Wellbeing).

In May 1913 the sixty-sixth World Health Assembly approved the Global Action Plan 2013-2020, a global strategy directed towards promoting mental wellbeing, preventing mental disorders, providing treatment, improving the possibilities of recovery, and promoting human rights and reducing the mortality, morbility and disability of people with mental disorders.

This plan is connected conceptually and strategically with a series of other plans that have been approved since 2008 in contiguous sectors and was drawn up in consultation with the member States, civil society and other international partners.

This action plan has the following goals: strengthening effective leadership and governance in the field of mental health; providing in an EU context complete services for mental health and social assistance that are integrated and suited to needs; implementing strategies for promotion and prevention in the field of mental health; and strengthening information services, scientific evidence and research in the field of mental health.

Each objective is accompanied by a series of actions proposed for the States, for the various national and international partners, and for the WHO secretariat, for which monitoring through periodic reports based on indicators is envisaged.

For Italy, which signed all these international documents, the data that are available also document a rising trend in the prevalence of the principal mental disorders, with which are associated various levels of disability, individual sufferings and sufferings of the family network, as well as economic and social costs.

The Ministry of Health also takes part in the Joint Action of the European Commission which started in 2013 and which is based on the work that led to the European Pact on Mental Health and Wellbeing (2008) and then to the Conclusions of the Council of the European Union on the European Pact (2011), and has entrusted to the regional government of Veneto European coordination of the area of mental health of young people in a school context. This Work Package seeks to define a framework of action for cooperation between the socio-health-care sector and the sector of instruction for the prevention of mental disturbance and the promotion of mental health and wellbeing, seeing the completion of the educational pathway for children and adolescents as an integral part of a framework adopted in common for Europe for the promotion of mental health and wellbeing.

Awareness of the complexity of the phenomenon of autism, with all its implications for the maintenance of the fabric of the family and consequences of a social character as well, has thus always required and obtained an urgent and concrete commitment on the part of central and regional institutions, in close agreement with the associations of family relatives.

The presence of targeted actions both at an early age and in adulthood would, in fact, allow a reduction – in a way that is easily demonstrable – of the direct and indirect heavy costs of autism. The necessary commitment must be directed towards the development of a capacity to govern complex phenomena, which is indispensable in addressing the need for a pathway of care and assistance that guarantees the principles defined by the existing rules in force as regards the right to socio-health-care assistance and to education that is non-discriminatory.

In particular, a network of specialist health-care services should be developed involving diagnosis and treatment that are accessible and homogeneously widespread in all the regions of Italy, assuring a multi-professional and interdisciplinary approach in order to be able to face up to the complexity and the heterogeneity of autistic syndromes and supporting families and supporting the processes of the school and social inclusion of people with autism, whatever their age may be. Some Italian regional governments have activated themselves in this direction but there is no uniformity of approach in the management of autistic patients. At a local level there is an absence of services equipped with all the figures needed for the treatment and care of patients and their families. Agreement and coordination between the various health-care sectors involved, as well as the integration of health-care action and school, educational and social action, and public services and services of the private social sector, families and their associations, is essential.

These considerations, and the need to provide support to these actions which are pointed to as being necessary, led the Ministry of Health to draw up at a national level in cooperation with the Higher Institute of Health and in agreement with the regional governments a guideline which can be defined as an authentic *Action Plan* for improving the quality and the appropriateness of action in this sector, bearing in mind, as well, that in October 2011 the Higher Institute for Health Care published its guidelines for 'The Treatment of Autism Spectrum Disorders in Children and Adolescents' which covered the most specifically clinical aspects of such action.

The Action Plan (*'Guidelines for the Promotion and the Improvement of the Quality and Appropriateness of Care Policies in Pervasive Development Disorders (PDD) and Autism Spectrum Disorders'*) was approved as an agreement at the session of the unified conference of 22 November and is thus fully operational.

The principal critical points that the document addresses can be summarised as follows:

- First of all, the overall approach to the person, understood as an authentic change in paradigm which pays due attention to rights, needs but also potentialities.
- The need to spread in capillary fashion early diagnostic processes because autism is an early pathology of the central nervous system and can generate complex disability.
- The immediate consequent need to construct a complete network of health-care services which is easily accessible and also widespread in the local areas.
- Awareness that the action that such services are able to offer is based upon multi-professionalism and interdisciplinary synergy.
- The impossibility of departing from a strong integration of the health-care, social, school and education dimensions if one wants to assure a holistic approach.
- Establishment of an indispensable guarantee of continuity in taking care of a person for his or her entire lifespan, with a steady adaptation of the action taken and the organisation of life spaces.
- The importance, lastly, of the promotion and strengthening of research in this area.

The plan provides homogenous recommendations for the planning, implementation and testing of activity to help minors and adults with autism in order to strengthen the network of services and thus to improve their performance, fostering agreement and coordination between all the operational areas involved. The capillary implementation in the various regional areas of what is envisaged will allow a better declination of the answers to the specific needs of the various local areas, although the essential and standardised levels of recommended services and pathways of assistance will remain the same.

In order to support the application of the plan in a better way, the Higher Institute of Health also set in motion, with the support and the cooperation of the General Department for Prevention of the Ministry of Health and in agreement with the special committees for health care of the regional governments, *an empirical survey of the network of services that operate in Italy* to help people with autism spectrum disorders and their families in order to create a dynamic map of what already exists. The aim was thereby to offer an updated picture of the supply from which to start in order to achieve an epidemiological characterisation of the phenomenon and the response at the level of care, directed towards directing in a better way the strategies for socio-health-care planning at a national, regional and local level. The form to be filled up to provide information, which was drawn up by the Higher Institute of Health Care and the Ministry of Health and presented in January 2013 to the Inter-regional Coordination Agency, is collecting the first data.

Lastly, the subject of autism was also placed amongst the priorities to be addressed within the '*Nation-*

al Action Plan for Mental Health' which was approved by the unified conference on 24 January 2013 and bore witness to the need to integrate the various institutional, organisational and clinical approaches to the problem, which is of a complex nature, and also in order to assure continuity in care in the move from childhood and adolescence to adulthood.

This planning document has the aim of re-launching the necessary priority actions in this sector both to obviate the critical aspects and to implement good practices – with especial reference to action for depression; to achieve continuity in taking responsibility for and providing support to families of problematic patients; and to achieve the overall organisation of the system of taking responsibility for mental disorders during childhood and adolescence.

From this general strategy comes a series of other operational documents which will help promote greater appropriateness and efficacy in the policies implemented by the regional governments which are directly responsible for the organisation of assistance. ■

SECOND SESSION
RESEARCH, PREVENTION AND THERAPIES

1. The Role of Environmental Exposures in the Aetiology of Austism. A Retrospective View of the Last Decade: New Results and New Frontiers for the Future

PROF. PHILIP J. LANDRIGAN MD, MSC, FAAP
Dean for Global Health,
Ethel H. Wise Professor & Chairman,
Professor of Pediatrics,
Department of Preventive Medicine
Icahn School of Medicine at Mount Sinai,
New York, USA;
Adjunct Professor of Environmental Health
Harvard University School of Public Health,
Boston, USA

Introduction

Autism is a complex, serious, biologically based disorder of brain development that most commonly becomes evident in early childhood. Social deficits, abnormalities in communication, repetitive behaviors, and cognitive inflexibility are the characteristic features.[1] Autism was first described in 1943 by Kanner,[2] and the diagnosis is based on clinical and behavioral assessment. There is no specific biochemical indicator or distinct neuroanatomical abnormality that characterizes autism.

Cases of autism vary from mild to profound and in the relative prominence of particular features and co-morbidities. Approximately 70% of autistic children are mentally retarded, some have abnormally increased brain size, one-third have had at least two epileptic seizures by late adolescence, and about half have severely impaired speech.[3] Yet some children with autism, notably those with Asperger's Syndrome, have highly developed intellectual skills, sometimes in specific areas such as mathematics.

The causation of autism is the subject of intense inquiry.[4, 5, 6, 7, 8] Genetic factors are clearly important. Gene mutations, gene deletions, copy number variants (CNVs) and other genetic anomalies are all persuasively linked to autism.[9] But none accounts for more than a relatively small fraction of cases. Also genetic factors alone do not fully explain key clinical and epidemiological features of autism. The hypothesis therefore arises that early environmental exposures may also contribute to causation, perhaps acting in concert with inherited susceptibilities that convey liability to autism.

This essay explores the possible contribution of early environmental exposures to causation of autism, with particular focus on the possible role of toxic chemicals. It proposes a strategy for discovery of presently unrecognized and potentially preventable causes of autism. Prevention of disease is the the ultimate goal of this discovery strategy.

Epidemiology of autism

The prevalence of autism reported currently in the US is one case per 68 children.[10] This prevalence is substantially higher than that of a decade earlier, and similar increases have been noted in the UK, Europe and Japan[11, 12] The CDC survey that established the current US rate found no significant difference between Caucasian and African-American children. It confirmed previous reports that ASD is 3 to 5 times more common in boys.[10]

This reported increase in prevalence has triggered vigorous debate as to whether the trend reflects a true increase in incidence, or merely an expansion in the definition of ASD plus greater awareness, improved diagnosis and better reporting.[11] This highly controversial question is not yet fully settled, but it appears that better recognition and improved diagnosis account for no more than about 25% of the reported increase in prevalence and that a true increase in incidence has occurred.[12]

Genetic factors in autism

Genetic and familial factors are unquestionably involved in causation of autism[4]. Families with multiple cases have been described. Autism has repeatedly been seen in sibs and twin pairs.

Concordance in monozygotic twins is reported to be greater than 70%. Families with autistic children may also contain members with "autistic traits" such as social isolation or tendency toward repetitive behavior.[13] Autism occurs in a number of genetic conditions, among them Fragile X Syndrome, Down Syndrome, Cohen Syndrome, Angelman Syndrome[14] and Rett Syndrome.[15] Some investigators have argued that as many of 90% of cases of autism are of genetic origin.[4]

Ongoing research into the genetics of autism has employed three main strategies[16]

(1) Family-based and case-control evaluations of candidate genes.[17,18] These studies have identified numerous candidate loci, most consistently on chromosomes 7q, 15q and 2q[17,18] They have also identified specific mutations associated with ASD, notably in *SHANK3*, a gene which encodes a synaptic scaffolding protein; in *NLGN 3/4*, also involved in synapse formation; and in *PTEN.*[14]

(2) *Cytogenetic studies*. Like linkage studies, cytogenetic studies have also identified abnormalities on chromosome 15q [17].

(3) *Genome-wide association screens*. [9,19] These studies, the most recent generation of genetic investigations in autism, have identified large-scale genetic duplications, deletions and CNVs associated with ASD. These include CNVs in *CNTN4*, a gene involved in development of neuronal networks; in *NRXN1*, involved in synaptogenesis;[19] and a recurrent microdeletion on chromosome 16p.[20,21] Each of these microdeletions accounts for approximately 1% of cases of ASD.

Shortcomings of a Purely Genetic Explanation for Causation of Autism. A purely genetic explanation for causation has difficulty in explaining important clinical and epidemiological aspects of autism. These include occurrence of sporadic cases, wide spectrum in clinical presentation, discordant development in monozygotic twins, and occurrence within families of members with fully developed autism side by side with others who manifest only "autistic traits".[7, 18] Some of these features could be explained by a medley of genetic factors - new mutations; *de novo* deletions, duplications or CNVs; and differential gene expression. But the need to invoke so many factors in postulating a purely genetic etiology is awkward. Moreover, a purely genetic explanation fails to account for the recent rise in reported prevalence of autism. This situation therefore raises the hypothesis that environmental exposures could also play a role in causation of autism.[7, 18] These factors could act in concert with genetic susceptibilities or through inducing epigenetic changes.

Further support for the view that genetic factors may not be the sole causes of autism comes from a National Academy of Sciences report, which concluded that 28% of all neurodevelopmental disorders in children result from early environmental exposures - 3% from environmental factors acting alone, and another 25% from interactions between environmental exposures and individual susceptibilities.[22] The Academy defined "environment" to include nutritional and infectious factors as well as chemical exposures.

Plausibility for an environmental contribution to causation of autism

Positive support for the possibility of an environmental contribution to causation of autism comes from:

(1) Current understanding of the exquisite vulnerability of the developing human brain to toxic exposures in the environment; *and*

(2) Studies specifically linking autism to environmental exposures.

Vulnerability of the Developing Human Brain to Toxic Exposures. The developing human brain is understood today to be exquisitely susceptible to environmental injury [23] This vulnerability is greatest during embryonic and fetal life, and may be especially great in the first trimester of pregnancy.[24, 25, 26] There exist windows of susceptibility in early development that have no counterpart in the mature brain.[27]

Evidence that Chemicals can Cause Developmental Neurotoxicity. Today there are over 80,000 chemicals in commerce. These are mostly synthetic chemicals, and nearly all have been invented in the past fifty years.[28] Some such as antibiotics and disinfectants have profoundly benefitted children's health. But new chemicals have also been responsible for disease, death and environmental degradation. Classic examples of new chemicals found belatedly to cause great harm include asbestos, DDT, polychlorinated biphenyls (PCBs), diethylstilbestrol (DES), and the ozone-destroying chlorofluorocarbons (CFCs).

Children are at greatest risk of exposure to the 3,000 synthetic chemicals produced in quantities of more than 1 million pounds per year, high-production-volume chemicals. These chemicals are found in a wide array of consumer goods, cosmetics, medications, motor fuels and building materials. They are common in hazardous waste sites.[29] They are routinely detected in air, food and drinking water. Measurable quantities of several hundred synthetic chemicals are found today in the blood and urine of nearly all Americans, as well as in human breast milk and the cord blood of newborn infants.[30]

Long and tragic experience that began with studies of lead[31] and methylmercury[32] has documented that toxic chemicals can damage the developing human brain to produce a spectrum of neurodevelopmental disorders ranging from overt toxicity at high levels of exposure down to subclinical dysfunction.[33, 34, 35, 36] A growing list of chemicals is now implicated in causation of neurodevelopmental disabilities **(Table 1)**.

Can Other Chemicals Cause Developmental Neurotoxicity? The short list of chemicals identified here as human developmental neurotoxicants may be only the currently visible tip of a potentially much larger problem **(Figure 1)**.

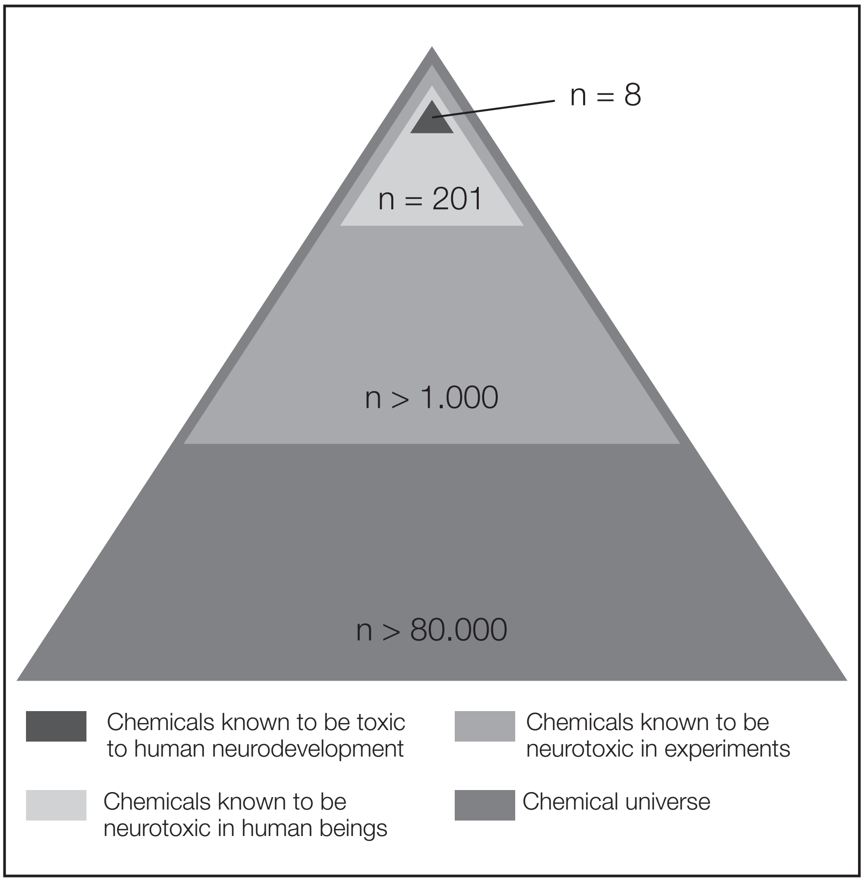
A recent systematic review of the world's literature undertaken to identify chemicals potentially

Table 1. Proven human developmental neurotoxicants

• Lead;[32,34,35]
• Methylmercury;[33]
• Polychlorinated biphenyls (PCBs);[37, 38]
• Arsenic; [39, 40]
• Manganese;[41]
• Organophosphate insecticides; [42, 43, 44]
• Organochlorine pesticides;[45]
• Ethyl alcohol[46] and other solvents
• Phthalates
• Bisphenol A
• Polycyclic aromatic hydrocarbons
• Brominated flame retardants (PBDEs)
• Perfluorinated compounds (PFOA and PFOS)

toxic to the developing human brain produced a list of approximately 200 industrial chemicals documented to be neurotoxic in adult humans.[47] These are primarily acutely toxic materials – metals, solvents, and pesticides. This search also produced a second list of approximately 1,000 chemicals that have not been examined in humans, but are neurotoxic in experimental animals. Given current knowledge of the vulnerability of the developing brain, likelihood is high that many of these chemicals have potential to cause injury to the developing human brain.

Figure 1. The iceberg (triangle) of developmental neurotoxicants. Reprinted from The Lancet, 368, Grandjean P and Landrigan PJ, Developmental neurotoxicity of industrial chemicals, 2167-2178, © 2006, with permission from Elsevier.



Failure to test chemicals for potential toxicity. A fundamental problem that impedes discovery of the environmental causes of autism is widespread failure to test synthetic chemicals for potential toxicity. Only approximately half of the 3,000 most widely used chemicals have been subjected to even minimal toxicological screening. Fewer than 20% of these chemicals have been examined for potential to damage the developing nervous system.[29]

Failure to test chemicals for toxicity represents a grave lapse of stewardship. It reflects a combination of industry's unwillingness to take responsibility for the products they produce coupled with long-standing failure of the US government to require toxicity testing of chemicals in commerce.[48]

Direct evidence for environmental causation of autism

The most strongly positive, "proof-of-concept" evidence to support the hypothesis that environmental factors contribute to causation of autism comes from clinical and epidemiological studies that link autism with specific environmental exposures.

– ***Thalidomide.*** An increased incidence of autism is reported among children exposed prenatally to thalidomide.[49] In a population of 100 Swedish babies with limb deformities exposed *in utero* to thalidomide, at least four met full diagnostic criteria for autism.[50] Based on the pattern of concomitant somatic malformations, the time of critical exposure was calculated to be 20-24 days post conception.[51]

– ***Valproic acid.*** Children exposed prenatally to the anti-convulsant, valproic acid, exhibit patterns of somatic malformation similar to those of thalidomide embryopathy, but of lesser severity. These include neural tube defects, cardiac malformations, cranio-facial anomalies and limb defects. They can also develop autism.[52] Autism was reported in 11% of 57 children whose mothers took valproic acid in early pregnancy. An even larger number of these children had some autistic traits. Based on the pattern of somatic malformations, the time of critical vulnerability was calculated to be in the first 3-4 weeks post conception.[53] *In utero* exposure of rats to valproic acid has been shown to produce behavioral abnormalities analogous to autism.[54]

– ***Prenatal rubella infection.*** Clinical and epidemiological studies have linked maternal rubella infection in early pregnancy with autism.[54] In these studies, autism occurred in conjunction with other anomalies typical of the congenital rubella syndrome, including eye defects, deafness, mental retardation and cardiac malformations. Risk for autism appeared greatest when infection occurred in the first eight weeks post conception.[52]

– ***Chlorpyrifos.*** Chlorpyrifos is an organophosphate insecticide widely used until a few years ago to control insects in schools and homes in the US and still used extensively in agriculture. Chlorpyrifos was first recognized to be a developmental neurotoxicant in experimental studies, in which perinatal exposure of newborn rodents to low doses of chlorpyrifos was shown to cause reduced numbers of neurons, decreases in intelligence and persistent alterations of behavior.[55]

Prospective assessments of children exposed to chlorpyrifos *in utero* reported significant decreases in head circumference, decreased body weight at birth, and slowed reflexes.[43,56,57] Continuing follow up through early childhood demonstrated significant developmental delays,[58] cognitive deficits and increased risk for attention deficit-hyperactivity disorder among these children. Most recently these studies have found, on the basis of maternal report, an increased incidence at 24 and 36 months of age of Pervasive Developmental Disorder, a form of autism .[46, 60] Recent epidemiological studies in California have found an elevated prevalence of autism in babies whose mothers resided during pregnancy in agricultural areas using pesticides.

– ***Automotive air pollution.*** Recent prospective epidemiological studies in California have found an elevated prevalence of autism among children whose mothers resided near busy freeways during pregnancy and who were exposed during gestation to elevated levels of traffic-related air pollution.

Timing of environmental exposures linked to autism. In each of the examples cited above the environmental exposures relevant to genesis of autism appear to have occurred prenatally, indeed very early in gestation.[50, 59] These findings have substantial implications for understanding the environmental causation of autism and for the design of research that seeks to discover new environmental causes of autism.[7]

Vaccines and autism?

Claims arose in the late 1990's in the UK, the US and other countries that childhood immunizations might be causes of autism.[60] In the United Kingdom, these claims focused on the MMR (measles-mumps-rubella) vaccine.[61] In the United States, claims focused on thimerosal, a preservative containing ethyl mercury added to multi-dose vials of many vaccines to prevent microbial contamination.

To address the issue, a series of studies were undertaken in the US, the UK, Europe and Japan. None of these studies have found any credible evidence for a link between vaccines and autism.[12] Key findings are:

– In the UK, there was a steady, year-to-year increase in the reported number of cases of autism from the 1980's into the late 1990's. There was no evidence of a change in this trend line following introduction of MMR vaccination in 1988.[62, 63] In a British series of 498 cases of autism, there was no difference in age at diagnosis of autism between vaccinated children and children never vaccinated. There was no temporal association between MMR vaccination and onset of autism.[66]

– In California, continuous increase in the rate of diagnosed autism occurred from the 1980's into the 1990's, but did not correlate with immunization patterns. Thus, autism cases increased from 44 per 100,000 live births in 1980 to 208 per 100,000 live births in 1994 (a 373% increase), while in the same time period, MMR coverage increased from only 72% to 82%.[64]

– In Yokohama, Japan, the MMR vaccination rate declined significantly between 1988 and 1992, and no MMR vaccine was administered in 1993 or thereafter. Despite declining immunizations, cumulative incidence of ASD increased significantly each year from 1988 through 1996 and rose especially dramatically beginning in 1993. Overall incidence of autism nearly doubled in those years.[65]

– In Denmark, a comparison of autism rates in 440,655 immunized children versus 96,648 unimmunized children in the years 1991-1998 found no differences in incidence or prevalence between the two groups. There was no association between age at immunization or season at immunization and rates of autism.[66]

– In Finland, a retrospective study in 535,544 1-7 year-old children vaccinated between November 1982 and June 1986 found no increases in incidence of autism during the 3-month period following immunization and no temporal clustering of autism hospitalizations.[67]

– In the UK, a prospective population-based cohort study that has followed more than 14,000 children from birth found no evidence that early exposure to thimerosal had any deleterious effect on neurologic or psychological outcome.[68]

– In the US, an analysis of neuropsychological function in 1,047 children found no consistent correlation between neuropsychological functioning at age 7-10 years and early exposure to thimerosal-containing vaccines.[69]

Taken together, this extensive series of high-quality, peer-reviewed studies has failed to show any association between autism and childhood immunization. Fear of autism does not justify failure to vaccinate children against life-threatening diseases.

Need for an autism discovery strategy

A systematic strategy for discovery of the environmental causes of autism is urgently needed. The rationale for seeking environmental causes of autism is that, once discovered, these causes are potentially preventable.[70]

A successful strategy for discovering the environmental causes of autism will need to be highly interdisciplinary. It will need to bring together researchers from outside of the traditional autism research community[12] from a wide array of disciplines including toxicology, epidemiology, developmental psychology, developmental neurobiology, neuropathology, molecular genetics, genomics, proteomics, functional neuroimaging and medical informatics.

Three key components of a proposed autism discovery strategy are:

Toxicological studies. To close current gaps in knowledge of the toxicity of synthetic chemicals, a highly targeted, legally mandated and strictly enforced toxicological search is urgently needed. The goal will be to identify chemicals that are developmental neurotoxicants. This search should begin with the 1,200 chemicals identified as neurotoxic in the literature review described above.[48] Highest priority should be assigned to those chemicals on these lists that are most widely distributed in children's environments.

New, more rapid screening tools for detection of developmental neurotoxicity are needed.[71] Also, to better detect the potential of chemicals to injure the developing brain, toxicity testing protocols need to expand to include examination of neurobehavioral function. Current test protocols rely mainly on such crude parameters as brain weight and gross morphology.[72,73] and are therefore insensitive.

Neurobiological research. To understand the cellular and molecular mechanisms involved in environmental causation of autism, a broad range of neurobiological studies need to be undertaken. These studies will discover how toxic chemicals interact with the developing brain, and identify the ways in which chemicals interact with the genome to produce changes in brain structure and function. Neuropathological and imaging studies will be critical.

Prospective Epidemiological Studies. Large-scale, prospective epidemiological studies are extraordinarily powerful engines for discovery of the environmental causes of autism. These studies enrol women during (or before) pregnancy, measure environmental exposures in pregnancy in real time as they are actually occurring, and they then follow the children to age 21 or beyond. Such studies permit specific linkage of prenatal exposures to diseases such as autism. The prospective design reduces recall bias and is crucial for studies that require accurate assessments of exposures in pregnancy.

Prospective epidemiologic studies are especially powerful when they incorporate biomarkers of exposure, of individual susceptibility, and of the precursor states of disease. Incorporation of genetic and epigenetic markers into epidemiologic studies creates opportunities to explore the role of gene-environment interactions and epigenetic alterations in disease causation. With increasing deployment of prospective biomarker-based epidemiological studies, the pace of scientific discovery in environmental pediatrics has accelerated markedly.

Conclusion

Much attention in recent years has focused on understanding the genetic contribution to causation of autism. This elegant research has linked a series of genetic factors with autism. But none of these anomalies accounts for more than a small percentage of cases. Moreover, genetic factors alone cannot readily explain many important aspects of the clinical presentation and epidemiology of autism, especially recent sharp increases in the reported prevalence of autism. This situation raises the possibility that environmental factors may also contribute to causation.

Expanded research into environmental causation of autism is urgently needed as a guide to disease prevention. Children today are surrounded by thousands of synthetic chemicals, but fewer than 20% of these chemicals have been tested for neurodevelopmental toxicity. There is substantial imbalance between the highly sophisticated information on the genetics of autism and the lack of data on potential environmental causes.

To discover and control the undiscovered environmental causes of autism, an interdisciplinary autism discovery strategy is proposed that combines toxicological screening, neurobiological research and prospective epidemiological study. Likelihood is high that this strategy will identify new environmental causes of autism. Potential for breakthrough discovery is high. The ultimate goal is the protection of our children's health and well-being. ■

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2. The Brain and Behaviour

PROF. FILIPPO DRAGO
Full Professor of Pharmacology,
University of Catania,
Italy

The high level of complexity and sophistication of social interactions is one of the fundamental characteristics of human behaviour. Autism spectrum disorders constitute a heterogeneous group of pathologies of neurological development whose diagnosis today is based upon detection of a deficit of a variable gravity in social interactions and verbal and non-verbal communication, and upon the presence of repetitive and stereotypical forms of behaviour. Some children manifest signs of retardation of their development during the first eighteen months of life, whereas in 25%-40% of cases there is a normal development up to age of 18-24 months, with a subsequent regression then taking place.

Overall, in individuals with autism one encounters an alteration in the relationship between the self and the environment and (according to so-termed mind theory) in that individual's ability to understand the wishes, the intentions and the beliefs of the other.

The areas of the brain involved in functions that are altered in autism make up the so-termed 'social brain', amongst which there are the frontal lobe, the upper temporal cortex, the parietal cortex, and the amygdale. Studies on autistic patients have shown the presence of neurobiological alterations that could explain functional deficits, such as an excessive growth during the first year of life in some of these areas, such as the frontal cortex and the temporal cortex. An explanation for this anomalous growth seems to be the presence of neurons which profoundly alter the formation of circuits in the areas involved. In addition, an alteration in the cortical organisation of mini-columns has also been encountered.

Some neuro-imaging studies suggest that the complete set of behavioural deficits that characterise autism could be explained by a compromising of the integrations of the frontal and posterior cerebral areas. The understanding and production of language requires functional coordination between the lower area (Broca's area) and the posterior upper temporal gyrus (Wernicke's area). At the same time, social behaviour requires a functional coordination of the medial frontal areas and the posterior areas such as the temporal-parietal junctions (associated with mind theory), the superior temporal sulcus (which is involved in the elaboration of movement), and the fusiform gyrus (which is involved in the elaboration of faces) Stereotypical and repetitive forms of behaviour can derive from reduced communication between the frontal systems, which guide attention, and the posterior systems for the carrying out of repetitive forms of behaviour. The availability of an intervention that can improve cerebral inter-regional communication could be useful in the treatment of autism.

It has recently been proposed that an early dysfunction in the mirror neuron systems can provoke the cascade of alterations which are at the base of autism. These are motor neurons that are active both during the carrying out and during the passive observation of specific movements with a purpose. The system of mirror neurons is involved in the understanding of actions and in other important aspects of social interaction, and could therefore be altered in pathologies that involve deficits in social abilities such as autism or schizophrenia.

One of the cognitive disorders, autism can be inherited in a high percentage of cases, suggesting an important connection more with genes than with environmental influences. In a large number of familial cases mutations in the genes of molecules involving synaptic adhesion have been found, in particular neurexin and neuroligin which have a fundamental role in transmission, as has been demonstrated by dramatic deficits in knock-out mice.

An early diagnosis of autism, allowing action to be taken during the early stages of this illness, often leads to an improvement of the outcome. At the current time a specific therapy does not exist but pharmacological treatment (anti-depressants, psycho-stimulants, anti-psychotic drugs, etc.) allows a reduction in symptoms and enables the patient to benefit in an optimal way from specific educational programmes.

The development of effective pharmacological treatment is necessary but it is complicated by the heterogeneousness of autism spectrum disorders.

3. The Role of Early Medical-Rehabilitative Therapy in Prevention

PROF. MARINA GANDIONE
Child Neuro-Psychiatrist,
Department of the Sciences
of Public Health Care
and Paediatrics,
University of Turin,
Italy

Autism spectrum disorders (ASD) include complex behavioural situations produced by a development disorder. They are present in all the populations of the world, in all races and in all social environments, and afflict male individuals three to four times more frequently than they do females.

A child with a confirmed diagnosis of ASD grows with his or her disorder, even though with time he or she can acquire new skills. According to the stage of the development of the disorder, new difficulties can emerge. The environment in which he or she lives, the appropriateness or inadequacy of the therapeutic initiatives, and the 'encounters' that the child may have in the streets, will certainly influence his or her growth and development. However, his or her functioning will always have an 'autistic' character.

The scientific literature in the field points out how early and intensive action improves the symptoms and the level of development of the child. The plasticity of the central nervous system during the first periods of life (the first 24 months) allows initiatives involving rehabilitation, or better enablement, to be more incisive and thus able to change the life pathway of the individual involved.

For this reason, in order to be able to address the multiple problems that such a variegated, grave and invalidating pathology, which at the present state of our knowledge is incurable, raises for therapists, it is of fundamental importance to start with diagnosis and the early outbreak of this pathology.

The first signs of an autistic condition, which is expressed in difficulties in the sphere of communication, interaction and behaviour, appear early on. Until not many years ago in the majority of cases children came to the attention of clinicians after being put in nursery schools where the comparison with their contemporaries made the 'special' characteristics of these children no longer deniable.

At the present time, certainly thanks to the sensitisation of paediatricians but also because of the great information available to parents on the subject, the moment of the first consultation has been brought backwards and it is increasingly the case that children between the ages of 12 and 14 months are brought to the attention of specialists.

An early diagnosis is not only important because it allows us to bring forward the beginning of appropriate therapeutic initiatives but also because awareness and knowledge about the problem on the part of parents and educators can, and must, be translated into environmental 'adaptations' and into forms of communication that can improve the prognosis or, whatever the case, limit inadequate approaches that inevitably worsen the situation. In other words, early diagnosis can allow 'prevention'.

It is certainly the case that the sending of paediatricians to specialist services as soon as the first signs of 'risk' are observed is of fundamental importance. For that matter, there are numerous instruments of screening that are able to highlight the individuals at risk. These are instruments that should form a part of the normal practices of health controls envisaged for the first years of the life of a child and thus allow early access to specialist centres so as to set in motion the tests that are necessary.

A clinical diagnosis is not in itself sufficient: to set in motion an *ad hoc* enabling action for the child it is necessary to 'know' his or her particular and original characteristics. In this sense, the clinical diagnosis must be followed by an accurate functional assessment so as to highlight his or her strong areas and areas of weakness, and, on these basis of this, arrange an individualised management of the case.

National and international guidelines agree in observing that a programme of intensive action distributed in the various contexts of the life of the child must be implemented early on.

The cognitive-behavioural features are seen as the first concern but the involvement of the family and of all the people who have responsibility for him or her is seen as being of fundamental importance as well.

It has already been emphasised how during the course of childhood the typical manifestations of autism change and this means that there is a need for a periodical and systematic updating of the functional assessment of the child in order to adapt the therapeutic programme to new needs, to new difficulties but also to the new resources that have emerged.

The recent publication of the DSM V (diagnostic and statistical manual of mental disorders) extended the criteria to which a clinic should be able to refer in its diagnostic work, thus allowing the identification and taking care of the most not precise, less typical, and perhaps grave, situations, and thus to have an impact on the development of the disorder and to assure that situations that are initially 'not grave' do not become 'grave' with time.

The distinction between different 'autisms' that characterised DSM IV was shown to be ineffective with time: a single spectrum of disorders better reflects our current knowledge about this pathology.

The three areas of symptoms of areas indicated by the DSM IV became in DSM V two in number: 1. Socio-communicative deficits; 2. fixed interests and repetitive forms of behaviour. The disorders are placed on a single spectrum. In fact, reference is made to autism spectrum disorders where there are different levels of intensity: level 1. (requires support); level 2 (requires significant support); and level 3 (requires very significant support).

It is also emphasised that autism spectrum disorders are disorders of neurological development that are present during childhood or early youth, but at the same time it is stressed that they may not manifest themselves to the full (and thus be recognised) before social requirements exceed the limited capacities of the individual involved or are masked by strategies that have been learnt during a subsequent age.

The early recognition of a particular way of functioning, of perceiving the messages that come from the environment of the child with autism must, it has already been said, be translated into the activation of enabling and therapeutic actions that involve all the contexts in which the child lives.

First of all, therefore, the family too often after the moment of the diagnosis has to wait on its own (at least in the reality I which we work) for an opportunity to accede to specialised services that are able to provide adequate therapeutic initiatives.

One initiative that one should be able to set in motion after the diagnosis is parent training. The principal purpose of this is make the parents increasingly aware of the particular functioning of their child and as a consequence to provide them with the instruments to interact with him or her.

This envisages a context of a group of parents who have the same experiences and allows a couple who are parents to feel supported and guided in their behaviour in raising their child, and to express and share through dialogue, with the help of specialists in educational strategies, the approaches, emotions and problems that they have experienced.

Specifically with these goals, in the context in which I work a project has been activated called ‘Growing Together with a Special Child’ in an experimental form. This works with children who have been diagnosed as having ASD and are under the age of four and their parents.

The young age of the five children involved in the project was chosen specifically for preventive purposes but also to try, at least in part, to fill the void full of questions and anxiety that is often created between the moment of diagnosis and subsequent actions that are not always appropriate or useful.

It has been necessary to bring together the resources of the workers of a number of institutions that in various ways deal with autism spectrum disorders: the St. Camillus Health-care Centre in Turin, the Service of Child Neuro-psychiatry of the ASL To1, the ONLUS Association CasaOz of Turin, and the Service for the Diagnosis of Autism Spectrum Disorders of the University of Turin, of which I am the director.

The goals we set ourselves were: sharing a common language on the pathway of the families knowing each other; recognising the points of strength and weakness of the children; and the identification of objectives to be established during the pathway of growth of a child according to his or her characteristics and particularities.

A cycle of meetings was proposed and planned with two (physically contiguous) parallel spaces, one reserved for the parents, one for the five children, on days and at times compatible with the needs of the families involved.

The group of workers taking care of the children envisaged a brain/psycho-movement expert as regards infancy, a psycho-educational consultant, an expert in play therapy and two educators. The professionals that the parents met at the various meetings were two child neuro-psychiatrists, a woman educator, a brain/psycho-movement expert as regards infancy, an woman expert in play therapy, a woman psychologist and a woman neuropsychologist.

The pathway envisaged six meetings which were arranged in the following way: first meeting: introduction and getting acquainted; second meeting: play and social interaction; third meeting: targeted observation and spontaneous communication; fourth meeting: effective communication within structured contexts; fifth meeting: behaviour and emotions; sixth meeting: conclusion and restitution of the pathway followed.

From the second meeting onwards, video-recordings of the activities engaged in with in the group of children were used with the parents. The experience was undoubtedly very interesting, fruitful, and certainly enriching for the workers. Above all during the last meeting suggestions, comments and emotions emerged from the parents which will certainly be used in the activation of the future initiatives of parent training.

To end this paper of mine I would like once again to emphasise the complexity of autism spectrum disorders.

The term ‘complex’ has multiple meanings, some of which are truly impelling with autism spectrum disorders: *not linear, unpredictable, complicated, made up of many element, which are manifested in multiple and contrasting aspects*, which are not univocal, and which are difficult.

The diagnostic approach must be complex, detailed and multidisciplinary in order to provide the clinic with all the facts and peculiarities of that individual, but also of the context in which he or she lives.

The therapeutic programme is complex and it will have to be periodically revisited, modified and adapted to the stage of development of the child and his or her new situation.

The lives of people with autism and their families is complex.

One of the most important tasks, but also one of the most difficult one for those workers who take care of them, is that of managing to ‘animate hope’, trying to find the right balance between ‘not deceiving’ and ‘sustaining realistic hopes’. ■

Thanks

In the first place to the children and their families and then to my colleagues of the Service for the Diagnosis of Autism Spectrum Disorders of the University of Turin, of the St. Camillus Health-care Centre of Turin, of the Service of NPI of the ASL To1, and of the workers of the ONLUS Association CasaOz, Turin. ■

FRIDAY 21 NOVEMBER

THIRD SESSION

THE EARLY DIAGNOSIS AND THE IDENTIFICATION OF AUTISM SPECTRUM DISORDERS

1. The BASIS Network: Studying Infants at Risk for Autism

PROF. EMILY J.H. JONES
PROF. MARK H. JOHNSON
Centre for Brain & Cognitive Development,
Birkbeck, University of London,
United Kingdom

Introduction

Around 1% of young children in the UK have a diagnosis of an Autism Spectrum Disorder (ASD). Although caused by a combination of genetic and environmental risk factors, ASD is currently diagnosed on the basis of behavioral symptoms. Children with ASD have difficulties in social communication, often show repetitive patterns of behavior and interests and may be unusually over or under responsive to sensory input. Such symptoms tend to emerge in early childhood, although many individuals don't have their condition recognized until adulthood. Co-occurrence of ASD with ADHD is very common, as is the presence of a range of associated conditions that include intellectual disability, depression, and anxiety disorders. Understanding the causes and consequences of ASD is critical to developing more effective intervention and support options for individuals and their families.

In the UK, the BASIS study (British Autism Study of Infant Siblings) is a UK-wide network dedicated to the study of infants with older siblings with ASD. The team behind BASIS, led by Professor Mark Johnson at Birkbeck College London and Professor Tony Charman at Kings College London have recently launched STAARS (Study of Attention and ADHD Risk in Siblings), which follows infants with older siblings with ASD and infants with older siblings with ADHD in the same protocol. Infants are studied at 5, 10, 14, 24 and 36 months. Methods used include electroencephalography (EEG) and Near InfraRed Spectroscopy (NIRS), both noninvasive measures of brain activity; eye-tracking, a way of studying what infants attend to; and measures of behavior, cognition and arousal. Following both groups of infants in the same protocol will allow us to compare and contrast the early developmental paths to the two disorders. Results from this study will enable us to ask whether there may be similar or different early markers for ASD and other conditions, such as ADHD, and whether there may be core paths that could be targeted by prodromal interventions. Further information can be found on our website: www.staars.org.

Why do we need more effective intervention options for ASD?

ASD is associated with reduced educational success and employment opportunities. For example, of a group of 68 individuals with ASD followed from age 7 to adulthood, only 12% were rated as having a 'very good' outcome (Howlin *et al.*, 2004). Only a few of them lived alone, had close friends or permanent employment. In addition to the personal costs, managing ASD also incurs huge economic costs to society. A recent review concluded that the cost of supporting an individual with ASD is around £1.5 million for those with intellectual disability, and around £0.9 million for those without an intellectual disability (Buescher *et al.*, 2014). Thus, there is a pressing case for providing more effective intervention and support options for individuals with ASD and their families.

Current treatments for ASD can ameliorate symptoms, but 70 to 80% of children currently maintain their diagnosis into adolescence and adulthood indicating that there is substantial room for improvement (Helt *et al.*, 2008). Intensive behavioral interventions can improve cognitive and language skills for children with ASD when started in preschool (e.g. Dawson *et al.*, 2010), and reduce the costs of care for children with ASD (Peters-Scheffer *et al.*, 2012). Intervention is more effective for younger than older children, and success is related to number of treatment hours (e.g. Rogers *et al.*, 2012). However, such programs are expensive and time intensive and there is currently no provision for such intensive intervention approaches within the UK National Health Service. Further, preschool entry into such programs requires the development of robust early detection and diagnosis systems that are not currently in place in the UK. The personal and economic impacts of ASD create a pressing need to identify more effective treatment and support options for individuals and their families.

Prodromal interventions

Current models for treatment of ASD typically require children to meet criteria for diagnosis before entering symptom-based intervention. However, interest in 'prodromal' interventions (applied based on the presence of early risk markers of a disorder, but prior to diagnosis of the full syndrome) is increasing across a range of conditions. One example is the recent UK NICE guideline for increasing the prescription of statins for those at risk of heart disease (NICE, 2014a). The use of prodromal therapies for mental health difficulties like schizophrenia are also becoming increasingly prevalent, and Cognitive Behavior Therapy (CBT) is recommended for individuals who are considered to be at risk of developing psychosis (NICE, 2014b). Developing prodromal interventions for ASD may also increase the efficacy of our approach to the condition. Indeed, new theoretical developments characterize symptoms of ASD as emerging from complex interactions between early-emerging vulnerabilities, and the child's experience of their environment (e.g. Jones *et al.*, 2014). For example, if children with ASD withdraw from social events they will reduce their opportunities for learning about other people. The provision of intervention prior to the emergence of the full-blown syndrome may allow us to prevent such cascading effects.

Developing prodromal interventions requires us to have a nuanced understanding of the cascading developmental paths that lead to the development of behavioral symptoms. Such work requires prospective studies of infants that are followed through to an age at which diagnosis of ASD can be made. This allows researchers to compare data from infants with or without later diagnoses, and thus identify early differences in neural processing, cognition and behavior. However, taking such an approach on a population level is very challenging. With a prevalence of 1%, researchers would need to study 1000 infants to identify a group of 10 who later developed ASD. Studying groups of infants who experience higher risk for neurodevelopmental disorders can increase feasibility. One such group is infants with a first-degree relative with ASD. The high heritability of autism (the extent to which variation in symptoms of the disorder can be attributed to genetic factors that are transmitted within families) means that about 20% of infants with an older sibling with ASD will likely later meet criteria for ASD themselves (e.g. Ozonoff *et al.*, 2011). Working with infants at familial risk thus means that researchers only need to follow around 100 infants to identify a group of 15 to 20 who later meet diagnostic criteria for ASD. The feasibility and power of this research approach has led to the development of a number of research programs focused on infants at familial risk for ASD (see Jones *et al.* 2014 for review).

Early detection: 'Red flags'

Identifying early markers of later ASD is important in identifying children at heightened risk who may be eligible for prodromal intervention approaches, and research into the early signs and symptoms of ASD is making significant progress. There are few clear behavioral signs of ASD in the first year of life. However, there may be clinically subtle early developmental delays in motor skills and patterns of early acceleration in head circumference that could have utility as early screeners (Samango-Sprouse *et al.*, 2014). Red flags for ASD can be more reliably observed in the second year of life and include lack of response to name, delays in language development or diminishing eye contact (Jones *et al.*, 2014). Any episode of skill loss ('regression') is of particular concern, and should trigger immediate referral for further assessment. Increasing awareness of these red flags may help to lower the average age of diagnosis in the UK, which remains around 5.5 years for ASD (Howlin *et al.*, 1999). This may be particularly critical because whilst there appears to be significant plasticity in developmental trajectories before age 6 for children with ASD (Pickles *et al.*, 2014), cognitive skills at age 6 are a strong predictor of adult outcome. Thus, provision of intervention before age 6 years may be critical to improving later functioning. Indeed, screening or surveillance approaches based on these red flags have been successfully trialled in a number of countries (e.g. Barbaro *et al.*, 2011). One important feature of the most successful approaches is that children are regularly monitored over several time-points. The early manifestations of ASD are very heterogeneous, and so some children's symptoms may emerge later than others. Considering change over time (e.g. loss of a skill between 12 and 24 months) can also be a more accurate way to identify children at high risk.

Ethical questions

Although evidence suggests that early detection and intervention can be effective for some children with ASD, concerns remain about widespread implementation of screening and treatment programs (NICE, 2011). Screening tools are never perfect, and will always identify a small number of children who may show early signs of ASD but who do not go on to meet criteria for a diagnosis. These 'false positives' may create unnecessary concern for families. Knowing a child is at higher risk for a neurodevelopmental disorder has the potential to influence the parent-child relationship (e.g. Wan *et al.*, 2013), with possible cascading effects on later development. However, this should be weighed against the stress experienced by families who feel there is something unusual about their child, but who have to undergo a protracted process for that to be recognized.

There are also ethical debates within the autism communities about the appropriateness of intervention provision to children who cannot make an informed choice about their options. Many individuals with ASD have significant strengths, like artistic ability, creativity, detail-orientation or skill with computers. It is critical to ensure that any intervention techniques do not diminish these skills. Further, the 'neurodiversity' movement argues that neurodevelopmental 'disorders' like ASD should instead be seen as individual differences; applying a disease model to these conditions is inappropriate. The neurodiversity movement is sometimes misrepresented as being against any form of treatment – rather, the goal is generally to move away from 'curing' and towards options that might enable individuals with ASD to reach their full potential (e.g. http://www.psychologytoday.com/blog/my-life-aspergers/201310/what-is-neurodiversity). Not all individuals with ASD will want to access treatment or intervention options, since not all individuals will feel that they have difficulties with which they need help. However, the needs of those individuals who cannot communicate and thus cannot contribute to debates in this area must also be considered.

Developmental disorders affect families as a whole

When considering intervention and support options for children with neurodevelopmental disabilities, it is critical to consider the family context. Many families with a child with ASD experience significant stress (e.g. Vohra *et al.*, 2013). Many children with ASD struggle to fit into regular daycare or nursery provision, and this can lead to higher rates of employment loss and financial hardship for parents. There are also higher rates of divorce in families of children with a disability, and parents often experience more mental illness. It is important to recognize that some of these difficulties may not be directly caused by having a child with a disability. Some may be related to societal factors, like difficulties in accessing appropriate clinical and educational services. Providing better support and clearer clinical paths for families may significantly ameliorate stress. Other difficulties for families may be related to the heritability of ASD. Because the conditions is genetically complex, parents and siblings sometimes express milder phenotypic features of the disorder (called the 'broader phenotype'). In addition, higher rates of mental illnesses like depression and anxiety may also relate to shared genetic liability, since there is a substantial degree of overlap in the genetic risk factors for many mental health conditions (Psychiatric Genome Consortium, 2013). Taking a holistic familial approach to intervention and support options may thus be critical.

Biomarkers and interventions

Work with high-risk infants makes identifying objective biomarkers for early ASD a reality. A number of labs have reported cognitive or neurobiological features of infants who go on to ASD that could have potential as early markers (Jones *et al.*, 2014). For example, 6-month-old babies who later develop ASD show reduced neural sensitivity to changes in eye gaze, a critically important communicative cue (Elsabbagh *et al.*, 2012). Between 2 and 6 months, infants with later ASD show declining interest in gazing at people's eyes (Jones & Klin, 2013). And between 6 and 12 months, infants with later ASD start to find it more difficult to shift their attention between two objects on a screen (Elsabbagh *et al.*, 2013). However, most of these findings currently represent group differences between infants with and without later ASD. This doesn't necessarily mean that these markers are predictive for individual infants. To evaluate this, researchers need to explore the sensitivity (the proportion of children with ASD who were correctly identified), the specificity (the proportion of children who don't have ASD who were correctly identified), and the positive predictive value (the chance of having ASD if you have a positive score on the marker). This is a critical step to moving this research from the lab to the clinic, because good biomarkers should have good sensitivity and specificity, and a high positive predictive value.

Researchers are also trying to develop new supportive interventions for infants at high risk of developing ASD. Teams in the US and the UK are currently testing whether parent-mediated interventions can help to support the development of infants at high familial risk for ASD. These interventions help parents to learn how to respond to an infant who may be communicating in different ways from a typically developing infant (Green *et al.* 2015).

Looking to the future

Research on early ASD is in its infancy. However, we are developing an increasingly clear understanding of early behavioral signs and symptoms of ASD in the first years of life. Research needs to increasingly focus on developing more effective prodromal interventions targeted at these periods, so that when infants or toddlers are identified as 'at risk' we have options to offer families. The resources that need to be devoted to these efforts are not trivial, but the potential economic, societal and personal benefits vastly outweigh the possible costs.

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2. Non-Invasive Instruments for the Early Diagnosis of Autism Spectrum Disorders: the NIDA Project

DR. MARIA LUISA SCATTONI
Coordinator for the Early Detection of Autism (NIDA), the Section of Brain Toxicology and Brain Endocrinology, the Department of Cellular Biology and the Neurosciences, the Inter-departmental Autism Group, the Higher Institute of Health Care, Italy

Autism spectrum disorders (ASD) are a relatively heterogeneous set of disorders of childhood and adolescence (1) that are characterised by socio-communicative anomalies in the presence of restricted and repetitive forms of behaviour, activities and interests. Recent epidemiological studies have reported a prevalence in the general population of 1 in 68. (2) This highlights how such disorders constitute a serious problem for public health. Given that this disability at a social level persists for the whole of a person's lifetime and requires complex care and treatment, autism spectrum disorders involve a cost for the national health-care system and a burden for families which is rather high. The estimated average cost of taking care of a person who has autism during the whole of his or her life is about 1.5 million euros. (3) Although autism spectrum disorders are present from the first months of life onwards (4,5), a diagnosis can be carried out in a reliable way only starting at the age of two because the diagnostic tests that are employed at the present time and are seen as a gold standard are based upon the identification of those behavioural symptoms which are most evident starting with this age. The study of what takes place during the first eighteen months of life of these children is of great interest because there is growing evidence that the early identification of a risk of autism or early intervention, even before the disorder has expressed itself to the full, can in a significant way reduce the interference of autism spectrum disorders in the development of the child and also attenuate the final clinical picture. (4) The identification of precise indices of risk is thus said to allow a monitoring of the development and integration of the child within a programme of surveillance and of capacity-building that is able to prevent or limit the establishment and the consolidation of those socio-communicative and behavioural anomalies that are typical of autism spectrum disorders. Various studies have identified certain anomalies in development during the first eighteen months of life (6,7) with a predictive value as regards a diagnosis of subsequent autism. Recently, in relation to the subject of the genetic origins of autism, research into indices has been directed towards the study of the first stages of development of the younger siblings of children who have themselves already been diagnosed as having autism. The category of siblings is, indeed, held to be at high risk because they have a risk that is ten times as high as the general population when it comes to developing an autism spectrum disorder. (8)

The Higher Institute of Health Care, in line with other European and American bodies of the same character, in the year 2011 established an Italian network for the surveillance and assessment of the development of the brains of children at high risk of autism spectrum disorders during the first eighteen months of their lives in the regions of Lombardy, Tuscany, Lazio and Sicily. This was done in order to identify children at risk of autism before the age of two and to carry out their rapid placing in a programme for personalised therapy. The Italian network for the early detection of autism spectrum disorders involves some of the most important clinical centres and research centres in Italy that deal with the diagnosis and treatment of autism. This network brings into play a multidisciplinary team made up of neurobiologists, child neuropsychiatrists, psychologists, therapists of the capacity for movement linked to the brain and the mind in children, bio-statisticians, and biomedical engineers.

The protocol involved envisages during the first six months of life the study of indices of wellbeing of the children amongst which are: attention to social stimuli (such as pictures of faces and biological movement, the movement that is typical of animated objects); a spontaneous capacity for movement (the movements that a child makes spontaneously when he or she is not stimulated); and some spectrographic characteristics of crying. The recordings are made ten days after birth, and at 6, 12, 18 and 24 weeks of age in the homes of the children who are taking part in the study. Our survey focuses on early movement and vocal repertoires because these are altered in children with autism spectrum disorders. In addition, the study of spontaneous movements, crying, and their association, are of great scientific relevance because both are a measurement of the health and the development of the central nervous system and can be studied easily and in a way that is completely non-invasive. A study of early social attention in these children, on the other hand, is motivated by the important forms of compromising of social interaction that is typical of individuals with autism spectrum disorders. It has been theorised that such forms of compromising can be associated with an anomalous functioning of those mechanisms which in children with a typical development assure, from the first days of life, preferential attention being paid to social stimuli. (9)

At the age of 5, 10, 14, 24 and 36 months, the families of the neonates at risk are invited to the centres for child neuropsychiatry that are involved in the study in order to assess the development of the children through the use of simple play sessions or structured interviews. Whenever specific difficulties are identified, the children are directed towards forms of early care and treatment. In addition, all of the children who are recruited, as well as their families, are subjected to a genetic screening in order to identify possible rare mutations and variants that are correlated with autism spectrum disorders.

The NIDA network was created with the aim of engaging in a research project but it is increasingly turning out to be a ‘social’ project because the families involved feel that they are followed and above all else supported. The children hitherto recruited by the NIDA have reached a total of 115, of which 85 have a typical development and 30 are at high risk. After the first four years of monitoring and assessment, three children have been diagnosed as having an autism spectrum disorder; another two have been shown to have retardation in their development of language; and a child aged twelve months has demonstrated anomalies in the development of his system of movement. All of these children were immediately placed within programmes of individualised therapy, reducing by one to two years the time of diagnosis (estimated approximately at 3-4 years) and by another two years as regards being placed in treatment.

Indeed, the purpose of the NIDA project is an early detection of autism spectrum disorders and the creation of an operational model that can be extended to the whole of the national territory of Italy and also be transferred to other contexts involving the study of those parts of the population that are at risk. ■

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3. Predictive Behavioural Markers of ASD in Neonates at High risk

PROF. LONNIE ZWAIGENBAUM
Professor at the Department of Paediatrics and Director of the Centre of Research on Autism at the University of Alberta, Edmonton, Canada

This presentation summarizes how behavioral signs of autism emerge early in life, and how these advances can help inform early diagnosis and treatment. Special reference is made to longitudinal studies of high-risk infants; that is, younger siblings of children with the disorder.

What ultimately motivates this research is the goal of earlier diagnosis. There are still many families who feel frustrated and unsupported by a health system that does not recognize the seriousness of their concerns about their children’s development. Indeed, despite advances in learning about early signs of ASD, the average age of diagnosis in North America remains 4 years or later, perhaps earlier (around age 3) in the UK. This represents a serious public health challenge that must be addressed by further developing our system of care, ensuring that community health providers receive appropriate training in the early signs and that referral pathways are in place to ensure timely access to specialized assessment and treatment services. Better characterizing how early signs first emerge, and the diversity of early expression in ASD, is not sufficient to address these broader systems issues, but can help inform these efforts. There is also broader scientific relevance to delineating the earliest expression of the ASD in terms of understanding underlying mechanisms, and in particular, to assess the relationship between brain and behavioural development and functioning in ASD.

This research is supported by international collaborations, including the Baby Siblings Research Consortium based in North America, in partnership with Dr. Johnson's UK BASIS group, and a new European Network, 'Enhancing the Scientific Study of Early Autism'. These consortia and networks are focusing their efforts on scientific discovery, taking advantage of common measures and pooled samples to maximize the power to detect early signs. These consortia are also focused on promoting uptake of new discoveries into practice, while at the same time grappling with clinical and ethical dilemmas associated with this line of research. Another essential partnership in this line of research is with families. Parents invest considerable time in this research, given the breadth of the assessment measures and multiple visits over time. This speaks to the remarkable dedication of these families, particularly in view of the other commitments and pressures in their lives, including those related to caring for the older sibling with ASD. There is also much at stake for these families. During the course of the research, it may become evident that their younger child is also on a path towards the diagnosis of ASD. The dynamic nature of early childhood development and the variable presentation of ASD raises important ethical questions that investigators must consider – for example, the nature of informed consent and parents' preferences regarding how information about early evidence of risk is communicated. These infant siblings begin as healthy research participants, whose parents consent on their behalf, but over time, may develop clinically significant symptoms that warrant supports and intervention. Although, at a minimum, we are obligated to offer 'standard of practice' in regards to clinical care, the reality is that generic development services may not be sufficient to address the needs of infants with emerging signs of ASD. Thus, the development of more specialized interventions (or adaptation of existing treatment models) more targeted to infants and toddlers with ASD has both been a tremendous opportunity in this research context, with potential to benefit the broader community, but also an ethical responsibility to infants and families participating in our research.

Progress in characterizing early development in ASD based on this collaborative infant research can be summarized as follows. First, defining symptoms of ASD (that is, behavioral features that can be clearly mapped onto standard diagnostic criteria, including those from ICD-10 and DSM-5) are present in many children with ASD by 12-18 months. Second, a broader range of features, including atypical patterns of visual orienting and motor dysfunction, have been reported in the first year of life among high risk infants later diagnosed with ASD. Some authors have referred to these features as 'prodromal' as they may be present prior to more characteristic features of ASD. Third, there is growing evidence of abnormalities in brain growth, connectivity and function in ASD in the first year, and thus which may also precede more overt behavioral features. Finally, although it may seem that researchers may be moving away from inquiring about parental concerns and focusing more on signs of ASD detectable within a laboratory setting, parents observations remain extremely informative.

There is considerable evidence of impairments in social-communication by around the first birthday. Several groups following high risk infants have reported reduced orienting when the child's name is called, reduced smiling and shared positive affect during social interaction, and overall reduction in social engagement (e.g., reduced eye contact, directed vocalizations). There is also evidence of reduced initiation of joint attention (gaze shifts aimed at drawing another's attention to a common focus of interest) and gesture use. It is more difficult to comment on deficits on developing relationships (the third social communication symptom domain in DSM-5) since at a year the primary relationship is with parents, and no infant studies to my knowledge have examined interactions with other familiar adults and peers. Indeed, what limited research has been conducted indicates typical attachment behaviors in HR infants towards their parents, despite atypical social communication.

As well, there is considerable evidence of repetitive interests and behaviors emerging around the first birthday in infants later diagnosed with ASD. These include atypical movements which are not always present early in life, but when observed they are informative. Even more common are repetitive actions with toys, including tapping and spinning, and perhaps most often, unusual patterns of intense visual inspection. Atypical over- and under-reactivity to sensory input was added as a diagnostic symptom with the release of DSM-5, and we find evidence of this both from direct observation and parent report. These differences in reactivity can also be considered along the broad framework of variations in infant temperament.

There is also evidence of 'prodromal' symptoms that may precede more overt manifestations of autism. First atypicalities in visual orienting to faces have been identified, generally assessed using eye tracking technology, where an infants' gaze towards different elements in a visual scene on a computer screen can be distinguished and tracked over time. For example, there is a study by Warren Jones and Ami Klin, which examined where high risk (HR) infants look when presented with a video of a highly engaging adults. Infants were assessed monthly from 2 to 6 months, and then at regular intervals to age 3. Typically developing infants showed stable to somewhat increasing attention to the adult's face, including her eyes, in the first year. In contrast, infants who were later diagnosed with ASD showed a decline in time spent looking at the adult's eyes, in contrast to more time spent looking at the adult's mouth. In fact, the rate of decrease in looking at the eyes between 2 and 6 months was predictive of ASD within the HR group. There is also growing evidence that infants later diagnosed with ASD show atypical motor development. Several studies have shown both subtle delays in early motor milestones, accompanied by abnormalities in motor maturity; for example, persistent head lag.

Dr. Johnson, in his presentation, reported compelling evidence of atypical brain functioning in infants later diagnosed with ASD. There is also compelling evidence of abnormalities in brain structure in infants later diagnosed with ASD. For example, Joe Piven and colleagues from the Infant Brain Imaging Study in the US report both increased brain volume and atypical connectivity emerging after 6 months.

Finally, even as science and technology have advanced our understanding of how ASD develops early in life, I would like to emphasize the importance of parent concerns. Indeed, until recently, most of what was known about autism early in life came from parent's rich recollections of their children early in life. With the shift in the field to *prospective* study designs (that is, following infants forward to the age of diagnosis, rather than looking back), there recently has been less of an emphasis on parent concerns. However, when collected prospectively, these remain highly informative and, indeed, may identify behavioral features of ASD as early as our best behavioral research methods. Our group in Canada coded and analyzed parental concerns collected at each study visit from 6 to 24 months in 59 low risk infants and 162 high risk infants, blind to risk status and outcome. Concerns about early social and communicative behaviors as well as repetitive behaviors were associated with risk of ASD by 12 months of age, whereas concerns regarding sensory and motor development (as well as play interests) were more common among those infants later diagnosed with ASD as early as 6-9 months. These findings emphasize the importance of listening carefully and taking parents' concerns seriously.

In summary, studies of high risk infants have identified behavioral symptoms that map onto current diagnostic frameworks and can help predict risk of ASD by the first birthday. Technology based measures such as eye tracking as well as measures indexing brain function such as ERP may help detect risk status even earlier. There have also been important advances in developing and evaluating interventions for infant showing early signs of ASD, adapting evidence-based ASD treatment models using knowledge from developmental science of how infants and toddlers learn, including from everyday experience interacting with caregivers. However, it is important to acknowledge that there remains much to be accomplished in order to achieve the goal of earlier diagnosis for children across the autism spectrum. Internationally, the average age of diagnosis remains at 4-5 years or even higher. Knowledge of early signs is not the only barrier; rather, uptake of findings by community healthcare providers and access to specialized assessments and interventions remains a challenge, even in developed countries. There are far greater challenges in the developing world. Earlier detection and diagnosis of ASD remains a significant public health challenge internationally, despite the promising progress summarized in this presentation.

FOURTH SESSION

PHARMACOLOGICAL, BEHAVIOURAL AND INNOVATIVE TREATMENT

1. Rehabilitative and Pharmacological Therapies Based on Evidence for Autism Spectrum Disorders: the Contemporary Situation and Prospects

PROF. ANTONIO M. PERSICO
The Child and Adolescent
Neuropsychiatry Unit
and Laboratory of Molecular
Psychiatry and Neurogenetics,
the Bio-Medical University
Campus, Rome;
The Malfada Luce Centre
for Pervasive Development
Disorders, Milan

The treatment of autism draws upon both rehabilitative approaches and various pharmacological agents. One should, however, first and foremost make clear that the efficacy of a treatment, independently of whether it is psychotherapeutic-rehabilitative or psycho-pharmacological, must be established on the basis of an objective assessment that is also based upon the modern principles of medicine that is 'based on evidence' . One *must* therefore take into account 'randomised and controlled' studies, that is to say: (a) studies carried out with sufficiently broad samples of patients going through childhood; (b) studies in which controlled individuals treated with placebo, and who are homogenous as regards sex and age compared to the cases treated with the active principle, are analysed; and (c) studies that have a 'double blind' approach, that is to say where those providing the treatment or the patients do not know whether they are receiving the active principle or the placebo. In the case of a rehabilitative approach, one can define the defining and founding elements of a specific psycho-therapeutic approach and assess whether, and to what point, their presence or absence has an influence on the clinical development of the patient. The limits of randomised and controlled studies in the field of child neuropsychiatry are often debated and some alternatives have also been proposed (Persico *et al.*, 2015). However, this approach continues to constitute a founding element of the definition of the efficacy of an intervention. Thus studies carried out 'in the open', that is to say without controls and with the knowledge of the patients and those who administer the active principle, even though they involve a large number of cases, could at the most provide 'clues' as regards efficacy which would then have to be confirmed through randomised and controlled studies. Individual anecdotal observations must be seen as being even more preliminary and also not very reliable.

In the field of autism it is important to distinguish between forms of treatment that are 'based upon sufficient evidence' and those based upon 'still partial or insufficient evidential clues', and between those forms of treatment that have not been studied in a randomised and controlled way ('absence of evidence') and those forms of treatment that at the end of randomised and controlled studies have not revealed any influence on the clinical situation ('evidence of inefficacy'). This distinction forms the basis of the 'Guidelines 12' that were promulgated by the Italian Ministry of Health and the Higher Institute of Health Care in 2011 entitled 'The Treatment of Autism Spectrum Disorders in Children and Adolescents'. This important and courageous document, which in Europe was preceded only by the previous document of the Scottish Intercollegiate Guidelines Network entitled 'Assessment, Diagnosis and clinical Intervention for Children and Young People with Autism Spectrum Disorders' (2007), derived from a systematic review of the literature in the field and made a distinction between various therapeutic interventions on the basis of the level of evidence achieved which was defined on the basis of criteria which are defined and explained in the text itself.

Rehabilitative Therapies Based on Evidence

The rehabilitative therapies for

which sufficient evidence has been accumulated for them to be defined as being certainly effective are:

a) *Interventions mediated by parents*: here we are dealing with parent training together with various forms of intervention, generally of a cognitive and/or behavioural character, aimed at the child but acting through the parents (social communication parent training; joint attention parent training; parent training and day care; pivotal response training; individual target behaviour training; applied behavioural analysis or ABA). This kind of treatment has positive effects on the social communication and the problematic behaviour of children and adolescents; it also improves intra-familial relations and helps to make the parents feel that they are able to manage their children.

b) Behavioural interventions: in particular early intensive behavioural intervention (EIBI) based upon ABA. A derived form of treatment containing strong elements of pivotal response training is the 'early start Denver model' (ESDM) in relation to which, since the publication of the guidelines mentioned above, sufficient evidence of efficacy has been accumulated, and to the point of making this model perhaps the most incisive there is in the field of early intervention.

Therapies for which we have promising indications of efficacy but ones which are not yet definitive include the following:

a) *Special educational programmes*, such as TEACCH.

b) *Augmentative and alternative communication interventions*, such as the 'picture exchange communication systems' (PECS) and sign language.

c) *Cognitive-behavioural therapy*, which is useful above all else in the treatment of anxiety in cases of Asperger's syndrome or intense autism.

d) *Interventions for the strengthening of social communication*, which are based upon the use of social histories, new technologies, imitation training, peer groups, and training in mind theory.

Therapies that are not recommended because evidence exists on their inefficacy include the following: a) training for auditory support; b) facilitated communication; and c) hyperbaric oxygen.

Therapies for which there is not enough sufficient evidence to express recommendations that are safe as regards their efficacy or inefficacy in autism include the following: a) horse therapy; b) Tomatis sound therapy; c) traditional Thai massage; d) Qigong massage; e) physical exercise, *tapis roulant*; f) music therapy; g) diet supplements (vitamin B6, magnesium, omega-3 fatty acids); and h) a diet without gluten and casein, which is recommended only where there are measurable nutritional deficits or a demonstrated intolerance to these compounds on the part of the digestive system.

Overall, one should bear in mind, on the one hand, the extreme heterogeneousness of the clinical situation of autism which as a result requires extreme flexibility in establishing the rehabilitative project on the basis of the strong points and the weak points of the mental apparatus of the child. Secondly, the health-care worker should give priority to therapeutic approaches of proven efficacy. However, it is precisely the extreme heterogeneousness of autism that obliges us to abstain from a rigid dogmatism because even therapeutic approaches that are still not based upon sufficient evidence could be useful in specific cases. It is to be hoped that there will be an increase in that clinical research that seeks to define 'what type of rehabilitation for which child' and that this is done to make 'based on evidence what today is still based on experience' or on clinical practice alone.

Pharmacological Therapies Based on Evidence

Psychopharmacological treatment does not have any efficacy in relation to the specific symptoms of autism spectrum disorders (communication and socialisation deficits, repetitive forms of behaviour, rigid behavioural schemata and perseverance in them, and the anomalous processing of sense stimuli). However it does perform a task of great clinical utility when it is confined to that sub-group of individuals with autism spectrum disorders (children, adolescents or adults) who manifest, in association with autism itself, special problems which we could define as 'target-symptoms', such as aggression, self-injury, rage crises, hyperactivity, insomnia, depression, etc. Naturally enough, the use of psychotropic drugs, above all during childhood, should correspond to the following requirements: a) they should be effective in relation to behavioural target-symptoms; b) they should be without grave side effects and whatever the case they should have a favourable risk-benefit profile; and c) they should facilitate the cooperation of the individual concerned in the rehabilitative project.

The number of randomised and controlled studies for the use of medical products in individuals with autism going through childhood takes place on a modest scale. As a consequence, very few psychotropic drugs have been approved for use in a paediatric context in Europe and none of these apply specifically to autism (see table 2 in Persico *et al.*, 2015). Despite this absence, which imposes a frequently 'off-label' use of medical products above all in children and adolescents with autism spectrum disorders, the principal recommendations based on sufficient evidence produced by randomised and controlled studies are the following:

a) Aggression, irritability and self-aggression: this is a problem that is especially felt by patients and their families, most often with the advent of puberty, in males and in autistic individuals with grave intellectual disabilities. One should always know how to assess during the diagnostic stage whether the sudden intensification of these problematic forms of behaviour depend on concurrent pathologies of a medical character (toothache, physical pain, continuous constipation, gastritis, hypoglycaemia, etc.). Often these are forms of behaviour that are learnt and used by young people as a way of expressing a need or obtaining from their parents something that they want (in this case if the pharmacological treatment is not accompanied by parent training with the parents or a behavioural intervention upon the child, it will be difficult for the use of the medical product to be effective on its own). Whatever the case, randomised and controlled studies have demonstrated the efficacy of resperidon, aripiprazole, haloperidol and methylphenidate (this last only in cases that have a co-morbidity with ADHD and which respond to this medical product). Interesting examples of efficacy, but ones which need further studies, have been found with lanzapin, sodium valproate, la lamotrigine, clonidine and naltrexone.

Antidepressants that block the re-uptake of serotonin, for example fluoxetine, are ineffective if nor indeed injurious because of their ‘activating’ effect. It is important to observe that the efficacy of resperidon and aripiprazole has been demonstrated in prolonged treatment as well.

b) Hyperactivity and impulsiveness: rather frequent problematic forms of behaviour, due to a high co-morbidity between autism spectrum disorders (ASD) and attention deficit hyperactivity disorders (ADHD), seem to have an incidence of about 40% in individuals with autism. Efficacy has been demonstrated above all in the cases of methylphenidate and atomoxetine, whereas with clonidine and guanfacine evidence as to their efficacy is still insufficient. The first two medical products, however, in patients with ASD + ADHD, have an efficacy that tends to be less and an incidence of side effects that is greater compared to patients who only have ADHD.

c) Stereotypical and repetitive forms of behaviour: at least in some patients there is evidence of a certain utility of fluoxetine; the evidence is still of a preliminary character as regards resperidon and sodium valproate. In general, this is a symptom that responds less rapidly to pharmacological therapy, unless there is also the presence of a depressive correlate.

d) Insomnia: melatonin has a proven efficacy both at a clinical level and in connection with the production deficit which has been demonstrated to exist in many individuals with autism.

Various other pharmacological therapies have, on the other hand, been shown to be ineffective and they should thus be avoided (secretin, digestive enzymes, amantadine, etc). Naturally, these psychopharmacological therapies would have be supplemented by those that may be prescribed to treat convulsive crises and absences, which are present in about 30% of individuals with autism, at times where the pathology emerges in early infancy and at other times after puberty.

The choice of the medical product that is to be used naturally must be guided by a clinical judgement which, in addition to evidence as to its efficacy, bears in mind its potential side effects, the internal situation of the patient and the possible difficulties connected with the swallowing of tablets or hypersensitivity as regards smell. In the first case one should use medical products that are available in drops or in liquid form; in the second these last will produce a rejection that can be overcome using capsules or tablets, possibly ones that dissolve in the mouth.

Conclusion: Personalised Treatment (Rehabilitation and Psychotropic Therapy as the Future for the Treatment of Autism)

As autism spectrum disorders constitute an extremely heterogeneous condition, it is evident that the future of therapeutic action lies in a greater understanding of the mechanisms underlying the pathology in individual patients and in their correction through a targeted pharmacological therapy that is associated with personalised rehabilitative therapy. Various medical products are currently at stage II and III for ASD and associated pathologies or correlated with ASD (for greater information see Vorstman *et al.*, 2014, and Persico *et al.*, 2015). This approach will allow the obtaining of the utmost residual cerebral plasticity according to the age of the patient and the typology of underlying neurobiological alteration in the individual patient. In this kind of approach is to be found a reasonable and well-founded hope of being able to provide to children and adults with autism a quota of that social cognitive perception that their pathology is denying them.

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2. Complementary and Supporting Medicine: an Overall Vision

DR. CATHERINE DOYEN
The Service for Psychopathology in Children and Adolescents, the 'Sainte Anne' Hospital Centre, Paris, France

For children and adolescents who have autism, the recommendations of good professional practice encourage the development of overall programmes which include approaches connected with education and/or development whose efficacy has been assessed and demonstrated during the course of studies that have been rigorous at a methodological level.

In parallel with these conventional criteria, a large number of parents have resorted to non-conventional approaches, that is to say complementary or alternative approaches which are called in the literature in the field 'complementary and alternative medicine" (CAM) and which have been the subject of a large number of publications.

An approach is defined as being complementary where it supports conventional treatment, whereas an alternative approach replaces conventional treatment.

In the United States of America in 1992 the government wanted the establishment of an organ of control which was subsequently called the National Center for Complementary and Alternative Medicine (NCCAM). In France an equivalent institution does not exist for complementary and alternative medicine (CAM) but researchers and clinicians see here a challenge for public health in the future and are developing a number of programmes.

The NCCAM gives the following definition of complementary and alternative medicine: 'a group of diverse medical and health care systems, practices and products that are not generally considered to be part of conventional medicine'.

These approaches are many in number and can be described both with reference to the classification proposed by the NCCAM and with reference to holistic models such as those of the team of Kathi J. Kemper, or even more to the approach to the use of products that can be taken orally or products that cannot be taken orally.

The model of K.J. Kemper proposes a classification of the most frequent alternative or complementary medical products into four groups whose respective headings are biochemistry, lifestyle, biomechanics and bioenergy.

This alternative and complementary medicine is used in the United States of America with a frequency of 38% in adults and 12% in children, but other studies on autistic children indicate frequencies that go from 20% to 70%. More precisely, the Interactive Autism Network reported 381 types of CAM and observed that autistic children will receive during the course of their childhood and adolescence on average between five and seven types of CAM. According to James M. Perrin, in 2012 about 28% of children with an autism spectrum disorder received a type of CAM: in 17% of these this involved a kind of treatment and in 20% of these another form of CAM was present.

The reasons that lead the parents of children with autism to use these forms of CAM are first of all the observation that a single treatment, even of a conventional character, may not be sufficient for a clear improvement in symptoms. In addition, they fear in particular the secondary effects of pharmacological treatment. Other motivations that are equally adopted by parents and which were emphasised in the study of Ellen Hanson are that patients are looking for greater physical and emotional comfort, more empowerment, simplicity of access, a diminished level of invasiveness, a natural approach and, lastly, lower costs.

However, despite the frequent use of these approaches, the authors and researchers in the field emphasise the low methodological quality of the studies that have been carried out and the diversity of the results – these are elements that nurture controversy as regards the use of CAM. The methodology varies in the single case of controlled 'double blind' randomised tests. In this last case the team of Nicholas Lofthouse reviewed in a scientific journal twenty-five controlled randomised tests for examples of CAM with the use of products taken orally, and sixteen controlled randomised tests for examples of CAM with products not taken orally, which demonstrated benefits in autistic children. These authors thus formulated recommendations for the use of examples of CAM amongst which: melatonin, vitamins and minerals and therapies involving messages, as well as recommendations for the carrying out of future research in this area. They re-affirm the need for controlled double blind tests with a long-term follow up where a diagnosis of autism has been made. Although the repetition of the most promising research on CAM seems to be a rational prospect, they do not exclude a scientific interest in the carrying out of open, simple and inexpensive tests.

To end this article, alternative and complementary medicine for children with autism generates a great deal of hope in parents but it also produces very many controversies amongst health-care professionals. Parents and clinicians must be informed about their existence, sharing knowledge about them, in order to decide about their use or non-use. They should do all of this being the guarantors of the physical and mental health of the child but also, and perhaps above all else, to assure the wellbeing of the child and his or her family. ■

3. The Treatment of Children with Autism Spectrum Disorders in Low- and Middle-Income Countries: the Role of Non-specialist Treatment Providers

DR. MASHUDAT BELLO-MOJEED, MBBS, MPH, MSC CAMH
Child and Adolescent Mental Health Services,
the Federal Neuro-Psychiatric Hospital,
Lagos, Nigeria

Your Eminencies, Your Excellencies, Distinguished Guests, Parents and Unique Individuals with Autism Spectrum Disorders, Ladies and Gentlemen,

It is a great privilege for me to speak at this outstanding twenty-ninth international conference of the Pontifical Council of Health Care Workers. I thank the Catholic Church and the Pontifical Council of Health Care Workers for this opportunity to add a voice to those who invoke the urgent need of individuals with autism spectrum disorders.

Introduction

Autism spectrum disorders (ASD) make up a group of complex neuro-developmental disorders that afflict a child in early childhood. ASD is characterised by a persistent deficit in social interaction and social communication and restricted, repetitive patterns of behaviour, interest or activities (DSM-V). The presentation/features/symptoms of ASD vary in severity depending on the child’s age and intellectual and language abilities. The spectrum of symptoms in ASD ranges from mild to severe and are often accompanied by abnormalities in cognition, learning and sensory processes. Impairment in ‘social skills’, from which the term autism derives, include social-emotional reciprocity, non-verbal communication and relationship difficulties, while restricted repetitive patterns of behaviour include motor stereotypes (e.g. hand flapping), the repetitive use of objects (spinning), resistance to change, and restricted and fixated patterns of interest.

The Burden of Autism Spectrum Disorders

ASD has been identified as one of the leading mental health-related causes of the global burden of disease with lifelong effects on children. Over the past four decades there has been a consistent increase in the reported prevalence rate of children with autism worldwide. The rate of ASD increased from 0.4 per 1,000 in the 1970s to the current estimate of about 11.5 per 1,000. The relative dearth of research on ASD in low- and middle-income countries (LMIC) could partly explain the earlier assumption about the rarity of these disorders in those regions of the world.

The appearance of ASD in a family can impact negatively on the child, the family and society as a whole. Recent research findings have documented significantly high levels of psychological stress and burden in the family caregivers, especially the mothers of affected children. Although neuro-developmental disorders such as ASD affect children worldwide, its treatment is particularly challenging in LMIC where over 90% of children live. The increasing prevalence and burden of ASD indicates the urgent need for efforts to address the challenges of its treatment.

The Treatment of Individuals with Autism Spectrum Disorders

The treatment options for children with autism spectrum disorders can be categorised into pharmacological and non-pharmacological treatment (intervention) methods. Pharmacological treatment refers to the use of medication/drugs for challenging behaviour (such as aggression and self-injurious behaviour) and co-existing psychiatric or medical conditions. Although drug treatment has a role in the control of challenging behaviour and co-existing medical conditions, it is not the primary treatment method for core impairments in ASD. There is ample evidence to indicate the benefit of non-drug treatment, such as psycho-social and educational intervention, in minimising the core features of autism.

Non-pharmacological treatment of ASD includes behavioural, educational, social skill training (e.g. socialisation, play therapy and music therapy) and speech, language and behavioural treatment options. The aim of non-pharmacological intervention in ASD is targeted at minimising the core features of ASD such as social skill deficits, communication skill deficits and behavioural impairments. Given that the onset of the manifestation of ASD is usually prior to the age of three, early intervention is vital in achieving an optimal outcome.

Over 90% of children and adolescents in need of effective treatment for ASD live in the LMIC where they are exposed to the multiple challenges of extreme poverty, hardship and out-of-pocket costs for health-care services. In addition to difficult situations in the LMIC, and in contrast to the global reports of increasing prevalence of children with ASD, there is a serious shortage of specialists, especially in the LMIC, who can deliver available evidence-based effective treatment to individuals with autism.

Human Resource Challenges in the Treatment of Individuals with Autism Spectrum Disorders

Human resources are an important aspect in the treatment of children with ASD. Treatment of children with ASD involves various specialists such as child psychiatrists, developmental paediatricians, nurses, developmental psychologists, educational therapists, speech and language therapists, occupational therapists and physiotherapists. Specialists who can provide specific individualised treatment for individuals with ASD are scarce, expensive and associated with complex challenges. An acute shortage of trained specialists in the care of ASD in poor resource countries is well documented. Reports indicate that there is less than 1 psychiatrist per 100,000 in such countries and less than 1 psychiatrist per million in most LMIC. The estimated figure is seriously reduced in the case of specialists in the field of child and adolescent psychiatry. Compared with Western countries, the much needed services for early diagnosis and intervention for children and adolescents with developmental disabilities such as ASD are extremely scarce and limit access to much needed specialist care.

The use of non-specialists to deliver available treatment options have been identified as an economical and crucial alternative in bridging the treatment gap in ASD. The non-specialists used in the treatment of ASD have important defined roles in improving the scarce human resource in caring for affected children and their families. Examples of non-specialist treatment-providers include trained nurses, lay health-care workers, social workers, parents, family caregivers and teachers. Non-specialist treatment-providers are widely distributed in various sectors such as the health-care sector, the educational system, communities, and religious and other non-governmental organisations (NGOs). Worldwide, there are increasing efforts – including the development of effective treatment for use by non-specialists – which are geared towards scaling services for children affected with chronic medical conditions.

Task-Shifting as a Way Forward

Scientific evidence has shown that effective treatment exists for ASD and that the delivery of such treatment is feasible with the aid of unsophisticated technologies and non-specialised staff. The important role of non-specialists in the treatment of ASD evolves around the concept of task- shifting/sharing or skill-mixing to increase access to, and improve the quality of, the care received by individuals with ASD.

The World Health Organisation (WHO) describes task-shifting as 'the rational redistribution of tasks among health workforce teams'. In this case, specific tasks are moved, where appropriate, from highly qualified health workers to health workers who have fewer qualifications in order to achieve a more efficient use of the available health resources. In ASD treatment, task-shifting involves moving tasks from specialist health workers with higher levels of training in ASD to health workers with lower levels of training or task-sharing/skill-mixing amongst the different cadres of health-care workers. In this way, access to key health-care services for ASD can be increased in areas where there are currently acute shortages of specialists, especially in the LMIC.

The Roles of Non-specialist Treatment-providers in ASD

The roles of non-specialist health-care providers cut across the diverse needs of individuals with ASD. The roles of non-specialist health-care treatment-providers include the early identification of features of ASD. Early intervention is the key in an optimal treatment outcome for ASD but there can be no intervention/treatment in the absence of identification/diagnosis of the disorder. The World Health Organization (WHO) mhGAP (Mental Health Gap Action Programme) intervention guide is a useful tool for non-specialist health-care workers, such as those in primary health care, religious organisations and other non-governmental organisations, in assisting with early identification, diagnosis and treatment and the appropriate referral of severe cases.

Non-specialist health-care treatment-providers are important in detecting and addressing co-existing health problems and thereby achieving a better treatment outcome. They play an important role in promoting mental well-being, preventing other mental disorders, and ensuring adherence to outlined treatment and appropriate follow-up management of individuals with autism. Partly due to the complexities of autism spectrum disorders and the disadvantaged conditions faced by such children, especially in the LMIC, co-existing medical conditions such as epilepsy and sleep problems are common. With the aid of simple and short screening tools, non-specialists can detect emotional problems in family caregivers in addition to achieving the early detection of other health problems in children with ASD.

Social support groups are an important network for individuals with ASD and their families. The role of non-specialists in the treatment of individuals with ASD cannot be over-emphasised. The non-specialists can help affected individuals to improve their social and communication skills and be a part of self-help groups. They also provide an invaluable support for family caregivers, especially mothers. Research carried out in the LMIC has found that maternal caregivers in cases of ASD experience a significantly high rate of psycho-social stress and burden in caring for children with ASD. The support given to affected family caregivers will help to befriend affected individuals and their families. Such positive support will go a long way to reduce the high level of stigma associated with autism spectrum disorders because some families with affected children lock up their children due to their devaluation and rejection by society and the mark of shame associated with ASD.

Non-specialist treatment-providers are strong pillars in the delivery of psycho-social intervention, including appropriate psycho-education given to families on the nature of the disorder, its possible causes, available treatment options, and the instilling of hope in the family. Families/parents go through various phases in seeking help for children with ASD. The belief system and cultural practices in various LMIC can shape the pattern behaviour and the pathways involved in seeking specialist care. ASD and other neuro-developmental disorders are highly stigmatised conditions associated with a belief system that sees such a condition as a punishment by a maleficent god. Social stigma, when attached to ASD, often debars the families/parents of children with ASD from seeking medical help at an early age. The families of children with ASD often go down a tortuous pathway in search of information and a diagnosis for their affected children. The role of non-specialist treatment-providers is beneficial not only in providing much needed information on ASD but also in equipping families with the effective skills to manage child behaviour which can have a multiplier effect on that improved parental or maternal health which is required for improved health outcomes in their affected children.

Conclusion

ASD is a complex early onset lifelong neuro-developmental disorder. With increasing prevalence of ASD worldwide, and acute shortages of specialist treatment-providers in ASD, especially in the LMIC, increased efforts are needed to train, retrain and effectively supervise non-specialist health-care providers in delivering effective and evidence-based intervention for children with ASD through task-shifting/skill-mixing. Non-specialist treatment-providers in health sectors, religious organisations and other non-governmental organisations have important roles in the early identification, diagnosis, treatment and appropriate referral of severe cases. Appropriate attention should be given to task-shifting and the roles of non-specialists in the treatment of ASD to ensure the implementation of basic principles of social justice and equality in the provision and delivery of health-care services that are accessible, equitable and of good quality for all affected individuals. ■

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4. Between Resistance and Surrender: the Ethics of Research with Persons with Autism

DR. ROBERTO DELL'ORO
Director,
the Bioethics Institute,
Professor,
Department of Theological Studies,
Loyola Marymount University,
Los Angeles, USA

For Sandro

In this paper, I look at the question of research on autism, more specifically at the ethical criteria that ought to guide such an enterprise. Like other parents of children with autism,[1] I follow the research in this field with great expectations and hope; yet, as an ethicist, I am aware of the need to submit such effort to a more rational scrutiny. It is a difficult "balancing act," which might be described most appropriately with the linguistic pair made famous by the great German theologian Dietrich Bonhoeffer, when he refers, in his last letters from prison, to the dialectic of resistance and surrender.[2] Resistance: to the deterministic aspects of a condition parents would want to see overcome in their child, and this through research and experimentation for the sake of a "cure." Surrender: to the reality of an "autistic person," whose world, with the passing of time and the harsh realization that little truly works, becomes increasingly distant and unreachable, yet suggestive of a unique integrity. Of course such world is different from the world of non-autistic persons, yet it is meaningful in its own mysterious terms.

In this paper, I look at the following: (1) having distinguished between genetic research on the basis of autism and research on autistic subjects, (2) I will pose the question of what justifies biomedical research on persons with autism, given their almost universal inability to account for decision making capacity. (3) I will then look at standards for proxy decision making, with special attention to the applicability of the so the called "best interest standard" in therapeutic and non-therapeutic research. (4) Finally, I want to reflect on the notion of "autistic integrity," which, since the publication of the work of philosopher Deborah Barnbaum, poses the question of whether research on a "cure" for autism has any ethical grounding at all.[3] (5) Having taken seriously the conceptual dimensions entailed by such general, yet in my opinion, problematic *caveat*, I will conclude with a cautionary note on discouraging research on autism altogether.

1. Genetic Research on Autism and Research with Autistic Subjects

1.1 Genetic Research on Autism

Genetic testing is now available for more than one thousand and five hundred conditions, and, because of its implications, it generates a host of ethical questions. To begin with, there is to consider the special nature of genetic testing, which greatly expands the power of medical tests. Whereas most medical tests are diagnostic, in that they are designed to identify the problem after the symptoms have appeared, genetic tests can predict future diseases or the propensity for diseases long before the appearance of any symptoms. They do this by identifying healthy people who are carriers of disease-prone genes that might affect only their offspring. One can see that the vast predictive power of genetic tests sets them apart from traditional medical tests, mostly devoted to the diagnosis of symptom-causing problems. Since research on the genetic basis of autism involves, generally, the extended family in the search for genetic precursors, ethical principles with respect to autonomy and non-maleficence need to be taken into account.[4] With respect to *autonomy*, it is important to monitor the attitude of investigators, given widespread misconceptions about parents' responsibilities that, historically, have blamed them for the condition of their children. Such practice persists even today in the guise of misplaced admonitions, for example, that parents should not have vaccinated their child, should alter their diet, or have not adequately engaged in therapeutic play. There is, furthermore, the subtle coercion on family members to be part of research that comes with the expectation of a cure, the unrealistic hope that research participation will result in direct benefits to their autistic relatives. As for the requirements of *non-maleficence*, researchers must be aware of the possible impact of genetic detections on family members who are found to carry genes that might put them at risk of having a child with autism. The genetic testing of one individual often threatens the privacy of other individuals as well. The knowledge of carrying genetic precursors to autism can cause anxiety and distress in family members: if a person tests positive for such genetic predispositions, then that test also reveals that one or both of the person's parents might be carriers of the defective gene.[5] Furthermore, other members of the family, including relatives and children, are at risk of developing autism or of having a predisposition toward it, or of being carriers of the autism-causing gene. An inherited genetic defect is seldom a purely "private" matter. It is almost always a family matter as well. This raises the moral problem of communication: when might it be good for a person to inform family members of a genetic flaw that could also affect them? Conversely, when might it be good for family members to have access to a relative's medical record to learn something about their susceptibility to genetic risks for autism? The issue of privacy of genetic information, including those referring to autism, involves questions of insurability. Information stored on as microchip or in a computerized data base can be accessed by employers, government agencies, and insurance companies. Given notoriously nefarious practices of health care insurances with respect to "preexisting conditions," the information in question might put insurability in jeopardy.[6]

1.2 Autism and Human Subjects Research

In addition to genetic research, there is a second form of research, which uses individuals affected by autism as research subjects. A special set of reflections is warranted, in this case, with regard to research on children. Here the general criteria established by law and ethics apply also for the particular case of research on children with autism. This research can be *behavioral*, as in Sally-Anne or Smarties false-belief tests described by Uta Frith and Francesca Happé in their work,[7] or it can be *minimally invasive research*, for an example, genetic research that might involve blood draw. The regulations (C.F.R. 46, Subpart D) allow four kinds of research on children: (a) research with no more than minimal risk is permitted; (b) research with more than minimal risk is permitted if it is intended to benefit children; (c) research with a "minor increase" over minimal risk is permitted if it is likely to yield "generalizable knowledge" about the child's condition, i.e., knowledge that can be of benefits to others; finally, (d) research that does not meet the previous conditions, but which a panel of experts determines will present a reasonable opportunity to understand, prevent, or alleviate serious problems affecting the health and welfare of children, and which will be conducted in accordance with sound ethical principles and the assent of the children, is also permitted.[8] In the specific case of autism, research that includes *minimal risk as well as more invasive aspects* might refer to research into sensory difficulties described by persons with autism, which does not aim at a cure, per se, but at the alleviation of the symptoms in question. A more *invasive biomedical research*, aims at "curing" autism, as opposed to merely relieving symptoms. The central ethical questions, in this case, focus on the issue of informed consent, for the problem of decision making capacity of persons with autism obtains not only for the obvious case of research on children, but also for adults. Standards guiding research with less than autonomous subjects have been developed historically, and can certainly serve as a point of reference for our particular issue.[9] Still questions about the *specific* nature of the deficits faced by persons with autism, forces us to consider the issue of research in its most radical version: should we use persons with autism in biomedical research at all?

2. What Justifies Biomedical Research on Persons with Autism?

It is well know that the *principle of informed consent* represents the cornerstone in the ethics of research.[10] It is found in all major ethical codes, from Nuremberg to the Belmont Report.[11] Such requirement can be justified philosophically as the condition for "rescuing" the agency of the research subject, whose availability to experimentation risks functionalizing the person experimented upon to the ends pursued by science for the wider benefits of society.[12] The plausibility of such "means-end relation" is less problematic for the utilitarian, requiring, on the other hand, a higher level of justification for the Kantian philosopher. Still, for both the problem of justification rests upon a kind of "thought experiment" on the part of the research subject. The utilitarian justification assumes as a starting point the impartiality of a rational calculus of consequences, in which the benefit of the "greatest good for the greatest number" warrants the sacrifice of individual interest for the sake of social utility. For the Kantian, on the other hand, the impartiality rests upon the recognition that "to act in such a way that one's maxim can become a universal law," as in one of the formulations of the categorical imperative, entails seeing others as *others*, endowed with a dignity that deserves respect because it is not immediately subsumable under the finalities defined by personal interest, or the interest of society. In spite of their different starting points, for both, utilitarian and Kantian justification, a *theory of mind* is presumed as a condition either for recognizing the ends of social utility, or for understanding the requirements of the categorical imperative.[13] A lack of theory of mind, as defining the condition of the person with autism, entails, of necessity, failure to appreciate the demands of social utility, as well as those that ground "the humanity in others" as an object of absolute respect. The conclusion to be drawn here is that since none of the familiar arguments for the use of subjects in research can be convincing for persons with autism, the latter cannot be presumed to be competent "agents" in research, and this in the sense of possessing the very mental premises, such as a theory of mind, necessary for informed consent. But can we exclude categorically that, if not all, at least *some persons* with autism may be competent to offer informed consent? If so, what precautions ought to be in place for research to take place? More specifically, if competency, as stressed by most contemporary bioethicists, is to be seen as "decision-relative" (Buchanan and Brock), or "task-oriented" (Beauchamp and Childress), couldn't we assume that persons with autism might be excluded from high risk research, or from research based on a complex protocol, but not from a relatively simple research, which involves only minimal risk? Reflections on the ethics of *research with vulnerable population*, such as subjects with mental retardation, might offer suggestions on how to proceed with persons with autism.[14] In the former case, rather than excluding entirely persons with cognitive disabilities that affect decision making capacity -- a presumption obviously at odds with requirements of justice -- researchers focus on those competencies the individual subject has, tailoring informed consent, and in some cases, even the research itself, so as to best allow the subject to consent to the research process. In her work, Celia Fisher pleads for what she calls a "goodness-of-fit" ethic of informed consent, which, rather than concentrating on the deficiencies of potential research subjects, looks instead to "an examination of those aspects of consent setting that are creating or exacerbating consent vulnerability," as well as "considerations of how the setting can be modified to produce a consent process that best reflects and protects the consumer's hopes, values, concerns and welfare."[15] She describes her "goodness-of-fit" ethic as *relational*. The term, alluding to "responsiveness to the abilities, values and concerns of research participants" presupposes what I would call a "relational concept of autonomy," in which the agency of the subject is understood beyond individualistic parameters, as an expression of "connectedness to others" on the part of persons with mental deficiency: "Adults with mental retardation, like all persons, are linked to others in a relationship of reciprocity and dependency. A relational ethic calls for scientists to construct informed consent procedures based upon moral principles of respect, care, and justice guided by responsiveness to the abilities, values, and concerns of research participants and awareness of the scientists' own competencies and obligations."[16] But can "relationality," in the way Fisher seems to understand it, be assumed for persons with theory of mind deficit? Since the answer is negative, we are forced to the conclusion that biomedical research with persons with autism cannot be justified on the basis of a *pure autonomy standard*, such as informed consent. I think this conclusion is further buttressed by a careful look at the *conditions for competency*. Let me elaborate briefly with reference to the work of bioethicists Allan Buchanan and Dan Brock, who distinguish between two types of competency: one consists in the "capacity for understanding and communication;" the other in "the capacity for reasoning and deliberation."[17] Even if not all autistic persons are incapable of the latter, the former seems to present special problems for them on account of their theory of mind's deficits. Consider our authors' statement: "Understanding is not merely a formal or abstract process, but also requires the ability to appreciate the nature and meaning of potential alternatives – what it would be like and "feel" like to be in possible future states and to undergo various experiences – and to integrate this appreciation in to one's decision making… In light of these considerations, one has to conclude that to understand is to appreciate alternatives. More specifically to understand what is it to consent to a particular form of action is to understand what would happen if that action were not performed."[18]

Two difficulties emerge, when applying this notion of understanding to persons with autism. First, the "simulation theory" and "theory theory" debate shows that persons with autism might have difficulties with the abstraction that is required to employ counterfactuals that capture a kind of experience different from their own.[19] "Simulation theory" and "theory theory" present alternative conceptions of how behaviors by intentional agents are explained. "Simulation theory" avoids direct ascription of intentional states, and instead requires agents to merely simulate what they would do in a particular situation. "Theory theory," on the other hand, does require agents to ascribe intentions to others when explaining their behaviors. Both theories are problematic for persons with autism. "Theory theory" is immediately problematic, given the direct intentional ascriptions required. But also "simulation theory" presents challenges, given the difficulties persons with autism face with imaginative play, and with the appreciation of others' beliefs and preferences that are distinct from their own, as characterized in the unified consciousness view. It is clear that the ability to appreciate the nature and meaning of potential alternatives inherent in Buchanan and Brock's notion of understanding requires the same capacity as a successful employment of "simulation theory." Secondly, the significance of self-awareness to understanding in the account of Buchanan and Brock presents a problem. In their work, Frith and Happé have highlighted the *unique* nature of self-consciousness in persons with autism, one in which communicating the character of one's experiences to others becomes problematic for them. More specifically, the problem with communicating with others in persons with autism is not communicating per-se, but is being aware (self-consciousness) of what is being communicated. In the words of Frith and Happe', "…the logical extension of [theory of mind] deficit account of autism is that individuals with autism may know as little about their own mind as about the mind of others… Simply put, they lack the cognitive machinery to represent their thoughts and feelings *as* thoughts and feelings."[20]

I think the conclusion we should draw from these considerations, if it does not necessarily exclude all persons with autism from research, it does, at least, make it impossible to justify it on the basis of a pure autonomy standard. Criteria for competent decision making cannot be ascribed to persons with autism on the basis of the unique difficulties they face. At best, a *relational* concept of autonomy, such as the one articulated by Celia Fisher, might be of help, if it entails a willingness on the part of investigators to look for appropriate strategies in which informed consent might be demonstrated on part of the autistic subject.

3. What Standards for Proxy Decision Making?

If persons with autism are not competent to make decisions, then a surrogate or proxy decision maker will be asked to make decisions on behalf of the person. Two standards are normally invoked in this situation.[21] The first is the *substituted judgment standard*. According to this standard, surrogates make decisions for another agent based upon the agent's prior beliefs and preferences. If an agent has consented to a particular course of action, then that is what the surrogate should consent to on behalf of the agent. Thus the surrogate "substitute his judgment" for that of the agent on whose behalf he offers consent, according to the now incapacitated agent's own prior beliefs and preferences. Seen this way, the surrogate is someone who, given his knowledge of another's beliefs and preferences, has moral authority to speak on that person's behalf. Clearly, the substituted judgment standard presupposes that the person in question was at some point competent to make decisions. Thus the standard is invoked in the case of progressively worsening conditions that lead to incompetence, such as Alzheimer's. In the words of Devettere, "…proxies can use substituted judgment only when they know what the patient would have wanted."[22] But this is not the case with autism, for here there was never a time during which the person was in fact competent. Thus the substituted judgment standard is not an appropriate means by which decisions can be made to participate in research for incompetent autistic subjects. We need to explore another standard. A second standard is the *best interest standard*. According to this standard, an intervention is ethical if it is in the best interest of the incompetent person. A few caveats are in place, though, for "… the word 'best' in best interest is somewhat misleading and could be confusing. It does not mean that the proxy must provide the absolutely best treatment for the patient… The word 'best' in the best interest simply means that the proxy should decide on the basis of what he thinks is good for the particular patient – that is, what he thinks will truly benefit him."[23] In other words, the fact that the intervention is expected to be in that person's best interest has justificatory power over the lack of the person's consent. Typically, decisions made on behalf of very young children, or persons born with cognitive disabilities that affect decision making capacity, can be made utilizing this standard. It would appear that such is the case also for persons with autism, and yet it has been argued that participation in some biomedical experiments of adults with autism cannot be justified on the basis of best interest standard. Why? Let me clarify: the focus of the argument is not on research studies that are designated to investigate the nature of autism in non-invasive ways. In addition to genetic research, I mentioned before that behavioral research, or minimally invasive research is ethically unproblematic. The focus, then, is on biomedical studies, that is, research that is more invasive, and that is done with the aim of investigating potential *cures for autism*, such as remedies for theory of mind deficits. The unique way in which theory of mind deficits shape who a person with autism is has stunning repercussions for the application of the best interest standard. Perhaps the point can be made by introducing, first, the distinction between *therapeutic and non-therapeutic research*. While the designation between therapeutic and non-therapeutic has been contested, in the context of autism, one might refer to the former as research that may result in the partial or total restoration of theory of mind, and to the latter as research on the etiology of autism, but does not have the possibility of restoring theory of mind. As specified by the Belmont Report, all research, whether therapeutic or non-therapeutic, must be guided by the rule of proportionality, itself an application of the principle of beneficence: all human subject research must result eventually in greater net benefit than net risks. The distinction between therapeutic and non therapeutic research, however, depends on how the benefits accrue to the research subjects. In some cases, the research subjects themselves are benefited; in addition, future patients will benefit from the knowledge gained from the study. This is therapeutic research. In other cases, however, benefits are not expected to accrue directly to the subjects of research. Consider the case in which a new drug is introduced into a population to study whether the drug can be tolerated by the population, but without the goal to test for benefits to the subjects themselves. The drug may ultimately benefit the population in which the drug is initially tested, but the study was not designed with this expectation. One could say that, in this case, the benefits are not immediately real, but only *aspirational*, in that they may accrue to future patients, but not to the subjects themselves. Such is non-therapeutic research. It is important to consider that for the purpose of ethical considerations, benefits and risks do not divide along the same lines, for the risks of the research are borne primarily by the subjects. Therapeutic research is considered less controversial than research that results in only aspirational, non-direct, benefits. Why? There is the implicit assumption that, even with full and voluntary consent, some measure of autonomy is compromised in virtue of being a research subject. However, the trade-off in participating in potentially therapeutic research may outweigh the loss of autonomy. For this reason, non-therapeutic research, which does not confer the possibility of direct benefit to outweigh the loss of autonomy faced by the subject, is judged more ethically problematic. The *Declaration of Helsinki* sets out additional provisions for non-therapeutic research, precisely because of this assumption.[24] Sections 46.406-407 of the *Common Rule* make clear that research on children which carries greater than minimal risk, but which is not expected to benefit those children directly must meet the highest of standards before it can be approved. [25] The term "therapeutic misconception" was coined precisely because the errant assumption that non-therapeutic research might confer some benefits is rampant among potential subjects. This errant assumption places individuals in morally compromising situations: for example, individuals may agree to participate in research that is not expected to benefit them directly, trading in, so to speak, autonomy, for little, if any, direct benefit. [26] The clarification on the difference between therapeutic and non-therapeutic research brings us back to the question of the *applicability of best interest standard* as a standard of surrogate consent for persons with autism. The following arguments obtain here: (1) The best interest standard is only applicable when it is genuinely in the best interest of the person on whose behalf consent is offered to participate in research; (2) non-therapeutic research is not in the best interest of research subjects; (3) what if the research is not merely an investigation into the causes/nature of autism, or into behavioral aspects of autism, but research on adults into a potential cure for autism, with the possibility of that cure as one of the therapeutic benefits. Is this of benefit to the subject at all?

Let me confront at this point some of the arguments, such as those put forth by philosopher Deborah Barnbaum, who reject as beneficial such a research.[27] To live a full human life certainly entails the ability to enter into relationships of the kind that are not available to persons without a theory of mind. For sure it would be better for future children that they are born without autism. It is not clear that adults who have always lacked theory of mind would be benefited by gaining theory of mind in mid-life: who they are would be compromised tremendously by gaining theory of mind. Therapeutic research designed to benefit them may not be a benefit to autistic adults at all. What to make of the shift from a world in which full intentionality is not ascribed to other humans, to one in which others are rendered, all of a sudden, more complex? Can individuals who are non-autistic imagine what it would be like to move from the autistic into the non-autistic world? The complexity of the adjustment, in this argument, pertains to the sudden realization of the complexity of others' presence, of their "coming-into-being," so to speak, for the first time, a presence that is the result of a previously un-experienced *presencing*. But this entails also – and this is the second dimension – a coming-into-being of oneself as well, the discovery of "oneself as another," to borrow from a suggestive title of Paul Ricoeur, a new presence to oneself.[28] Being "cured" of autism requires a person to undergo radical reconsideration not only of other persons, but of himself. It requires adjusting oneself to a new way of being-in-the-world. If this is not a benefit to him, there is no reason to assume there will be aspirational benefits to be gained from this research either, allowing future adults with autism to be "cured." It is clear that in this perspective the best interest standard cannot be used to offer ethical justification for the use of adults with autism for research studies that have the therapeutic benefit of possibly restoring the subject's theory of mind. It is a stunning conclusion, which warrants digging more deeply into some of the *premises* of the argument. I will highlight three of them. First, the argument stresses the *uniqueness* of autism *vis a vis* other conditions. Such an emphasis seems necessary, lest one comes to the untenable position that no therapeutic research on any condition can be considered morally acceptable, insofar as it might entail a dramatic change in the person's being-in the-world. For an example, if one were to substitute "cancer," or "blindness" for autism, one could see how the argument runs into difficulties. But precisely here is the difference: autism does not merely change the way individuals interact with the world – it changes the very nature of the self, and the very nature of the other inhabitants in the world with whom the autistic person interacts. Blindness restricts the nature of communication with other persons, but it does not challenge a blind person's ability to interact with other persons *qua* persons. Consider the following observations of Barnbaum: "Narratives of illness are replete with descriptions of the ways in which cancer changes the relationship that people have with themselves, and with others. But the poignancy that characterizes these narratives results from the pain that can emerge from loneliness, isolation, or loss of relationships with others. The uniqueness of autism is that the pain in the loneliness, isolation, or loss of relationships is not necessarily as great, and in some cases, is not there at all."[29] A second premise: what about the aspirational, yet real, benefits of non-therapeutic research? Non therapeutic research may not be of direct benefit to the subjects, but it could contribute to knowledge about autism. Would it be possible to engage, at this point, Barry Brown's *cohort interest argument*, [30] as a way to forge a middle ground between the wide ranging good sought by the utilitarian argument for human subject research, and research that is expected to be only aspirational? We need to first confront Brown's argument, only to show that even his attempt comes up short when considering autistic research subjects. Brown considers the ethical quandary of individuals who cannot consent to participate in research, such as elderly patients with Alzheimer's disease. The question is: what could justify the use of persons with severe dementia in biomedical research, especially research that is not expected to be of benefit to subjects themselves? Brown suggests that such patients might still have surrogates make decision based on the substituted judgment that individuals have an interest in promoting the good for their community. This argument echoes one put forward, many years ago, by Catholic theologian Richard McCormick in discussion with his Protestant counterpart, Paul Ramsey, concerning the morality of using children in non-therapeutic research, an hypothesis Ramsey rejected on strict Kantian grounds. McCormick, on the other hand, supported the notion to an extent, and this on the basis of a "solidarity argument" that postulates some minimal responsibility of children toward others on account of their sharing in sociality: "If we can say of adults (who can and do have obligations) that it is reasonable to expect that they will want certain goods for others and contribute to these goods if there is no discernible risk, discomfort, or inconvenience, it is not because they are adults that we would conclude this, but *because they are social human beings* (emphasis in the text)."[31] Of course, one has to recognize that McCormick's debt to the *common good* tradition stands on an ethical ground that differs from a notion of social responsibility articulated in the neo-utilitarian language of self-*interest*! Still, Brown's argument seems very close to McCormick's. The decision to enroll a patient with advanced dementia in research "is justified by the claim … that it is for the common good of the dementia-care-research community, of which he is a member and to which, it is presumed, he would commit himself if he were capable of doing so at the time."[32] The presumption, in Brown's argument, obtains for both formerly competent and never competent patients. It is assumed that both populations share an affinity with the community of persons who do have this disorder. But is there such a thing as an Autistic community? There is an Autistic community comprised of persons without autism who care and advocate for persons with autism, but their interests alone cannot sustain the premises of the "cohort interest argument." It would not be ethical to claim that research on an incompetent subject is justified on the basis of the fact that some community, of whom that subject would never consider himself a member, has nevertheless an interest in that person's participation in the research. As Barnbaum suggests, "such a claim treads too closely to a justification of human subjects research on the basis on unchecked act-utilitarianism, which … cannot be invoked to justify human subjects research."[33] A third consideration: what if research on sensory difficulties were to lead, in the long run, to restoring theory of mind? Such research would target what Ramachandran and Oberman have termed the *salience landscape theory*.[34] According to this theory, the connections between the amygdala, which determines appropriate emotional responses to sensory stimuli, and the sensors themselves, is disrupted in persons with autism. The result is that the autistic person's salience landscape is not what it should be, rendering bright lights, high-pitched sounds, or scratchy clothing almost unbearable. As for the ethical question on the permissibility of research to remedy sensory difficulties, could the results of these treatments be thought of as akin to wearing sun glasses, restricting light, on the one hand, but allowing greater visibility, on the other? Especially in cases where sensory overload is causing a person with autism pain, it is clear that such research is of therapeutic benefit to the participant himself, as well as to future persons with autism. Thus such research is morally permissible, especially if it is done with children. In the case of young children, it is possible that their view of other persons as well as their own self-concept is not solidified, such that the acquisition of theory of mind would not prove to be harmful. Instead, the early acquisition of theory of mind would allow a child to ultimately experience the full range of human capabilities spelled out in various accounts of a theory of the good, from Martha Nussbaum's capabilities theory, to Thomas Scanlon's "substantive good," to Roberto Veatch's reconstruction of the "elements of well-being."[35]

The conclusions of the previous considerations on the best interest standard seem clear, at this point. I would summarize them in two ways: (1) children with autism may yet be able to acquire theory of mind without forcing them to radically re-think their notions of others and of self. For them, participation in research study that may hold out the possibility of a "cure" would be ethically justifiable. (2) On the other hand, such participation might not be justifiable for adults with autism. Rather than involving adults with autism in biomedical experiments that might drastically change their relationship with others and their understanding of self, adults with autism should be allowed to live out the lives the way they are. This calls for a respect for a life without theory of mind, and a notion of autistic integrity.

4. An Ethic of Autistic Integrity

The notion of "autistic integrity" questions the condition of autism as a disease in need of a "cure," pointing to the fact that being autistic is just that, a way of "being in the world."[36] The call for autistic integrity concerns those persons with autism who cannot recognize others in the fullest sense; second, it resigns to the notion that changing an autistic person into someone who has a theory of mind would require him to undergo a fundamental shift in the way he interacts with others, and comes to understand himself. The work of Uta Frith and Francesca Happé shows that people without autism do not know what it means to have autism, that is, what it would be like to have autism. Similarly, those who have autism do not know what it would be like not to be autistic. If parents are justified in making sure that their future children will not have autism, for adults with autism, this *desideratum* comes too late. Autistic integrity does not preclude admitting a theory of good, such as the one spelled out in various fashion by the philosophers mentioned above. To have certain goods/capabilities/ potentialities is, *objectively* speaking, better than not having them. Autistic integrity though, calls for the recognition of persons with autism as individuals with personalities and preferences of their own. Thus, to foist a cure on persons with autism is failing to recognize him as a person in his own right, because that cure assumes that the person would be better off cured. As spelled out above, whereas curing cancer or restoring sight to a person who was blind does not fundamentally change that individual *qua* person, restoring theory of mind would. For sure, an ethic that requires the non-autistic population to respect the differences of the autistic population places a burden on non-autistic society: it calls for a notion of distributive justice that provides autistic persons with the services they need. Distributive justice demands the integration of the person with autism into society, not unlike any other effort to integrate persons with disabilities into a society that often does not do enough to promote accessibility. According to Francesca Happé "the central coherence account of autism…predicts skills as well as failures, and can be best characterized not as a deficient account, but in terms of *cognitive style*."[37] If it is so, than the lack of theory of mind is simply the way some adults are. It would have been better for autistic individuals if, from birth, they had an intact theory of mind. Such persons would have been able to enjoy all the human capabilities, enter into full relationships, and speak the same moral language as non-autistic persons. But as adults, each person has to be appreciated for what he/she is.

5. Autistic Integrity: A Tentative Rejoinder

Let me conclude with a brief rejoinder to the autistic integrity account. I do so with full awareness of the value of such account, which, insofar as it stresses the singularity of persons with autism, *their* unique value and dignity, might even distinguish itself as morally superior. Autistic integrity speaks, on premises hard to understand at first, of what it means "to-be-in-the-world" *differently*. Thus, it also entails a call for acceptance and care beyond the obvious effort to return persons with autism to an essentialized definition of *normalcy*. To fail to accept the otherness of autism makes us all, the *others* to them, poorer, because closed to the richness of diversity, ourselves *autistic* in a sense, because disengaged from the vast realm of alterity, of which autism is just another dimension. And yet, I find the argument of autistic integrity ambiguous, if it entails the barring of a search for cure *for the sake* of persons with autism. This seems, at least *prima facie*, paternalistic and pretentious. I ask: how to discern, in the recognition of an "autistic integrity" without further qualifications, the fine line between commitment to the good of the autistic person, and capitulation to the complacency of resignation? More positively, how to galvanize the efforts of scientists, the generosity of parents, the solidarity of civic institutions, the call of churches to service of the vulnerable, if it all ends with a simple attestation of difference in "cognitive style"?

My argument is twofold. I look, first, at a cure for autism as a requirement of *commutative* justice, beyond the insufficient warrants of autonomy standards and beneficence highlighted so far. Second, I question on a philosophical basis the notion of an *absolute* discontinuity between autistic and non-autistic worlds; consequently, I also question the radical incommensurability of the life-worlds of persons transitioning from autistic self-enclosure to other-orientation and relationality. First, to cure autism is a requirement of *commutative*, rather than distributive, justice. The search for a cure is a *moral imperative* because *we owe* persons with autism what is *due to them*, on account of the fact that they share in our human condition.[38] To be human, for them as for us, is to be "given to be," a predicament that is neither conditional upon a choice on the part of the autistic person -- so that one would be free to accept or refuse such predicament from a position of neutral distance, nor depends upon the recognition of non-autistic others, as if the conditions for human belonging were to be defined by criteria of social acceptability. Thus, we cannot say for sure whether the person with autism would be better or worse off, were he to transition to a non-autistic reality, because such judgment would entail an all-encompassing viewpoint that, standing above two worlds, it includes them both. But the truth is that we live and make sense of the world around us, and of other human beings, from perspectives that can only be partial and limited, never completely wise, nor entirely ignorant. In our human condition, we are given to be in the enigmatic expectation of a *community* of being, of all beings, made possible by their openness to each other. Such anticipation of otherness at the heart of all new life (think of the child's expectation for the mother's embrace captured by the artist!) is not chosen, but given. We do have to reckon with the painful realization that the *gift* of such openness is not actualized by everyone, and perhaps will never be. And yet the therapeutic restoration of such predisposition to be filled by the other's embrace, and to reach out to the alterity that awaits human beings, is to be pursued not only because it is *deemed* a good in a list of selected capabilities, but because it is *given* to us as a dimension of our integrity of being, before our recognition of it as a functional value, or as a pleasure-producing quality. [39]

I come to a second rejoinder. The autistic integrity argument assumes the incommensurability of autistic and non-autistic worlds, thus postulating an absolute discontinuity between the two. At the same time, it fails to take into account the fact that the discontinuity of mental states, such as the passage from a lack to a possession of theory of mind, is grounded by the *continuity* of an embodied, temporal individuality.[40] How does such an underlying continuity affect the process of mental re-adjustment? What is the relation between self-consciousness and "emotive tonality" (Heidegger), or self-consciousness and time-consciousness (Husserl)? If the acquisition of a theory of mind represents a process of *coming to mindfulness* that involves not only the "mind," but the very "being" of the person, how can we predict a priori the results of such transition? Could it not be that "traces" of presence to oneself, rooted in the embodied and temporalized flesh of the person, provide the passage way, literally, the "metaphor" (*meta-pherein*) for a still to be fully articulated release into mindfulness? If that were the case then, to acquire a theory of mind is less akin to passing from not having to *having something* -- as in buying a house or winning cash in the lottery. Also, it cannot be like becoming someone else either, for, if the embodied and temporal preconditions of one's identity are to be taken seriously as conditions for becoming mindful, we can only become *more fully* what we already are. I think of the communication with my autistic son, the exchange of caresses, and kisses, and touches that has built, over the years, something like a "memory" of my presence in him, inarticulate for sure, perhaps even shrouded in a lack of awareness (does he know I am his father?), yet mysteriously recognized by him. It is *me* he feels in the abandonment of spontaneous trust, or the search for proximity at the startled realization of a foreign presence, a person, an animal, a scary thing. Isn't such "living in the flesh" of his already sparked with stray flashes of a more mindful intimation? Isn't this indeterminacy of *being* as elementally embodied a raw anticipation of a more fully coming to mindfulness, as in a fully developed theory of mind? And how could he gain the latter without the former?

All this must be developed further, for sure. But it seems to suggest that the recognition of the otherness of autism notwithstanding, of its mysterious integrity, can still coexist with the effort to bring such unexpressed intimacy into a gift for others, a gift for us. This is why I say, let the search for a cure continue!

Notes

[1] I do consider myself less than an "expert" on autism, except that the adventure of parenting a child with autism has forced me and my family to reckon with a world previously unknown, leading us all through an experience both puzzling -- indeed at times, disconcerting -- and full of grace. We have been in this journey for the past sixteen years, since my son Sandro was diagnosed, at the age of two, on the autistic spectrum disorder.

[2] Dietric Bonhoeffer, *Widerstand und Ergebung: Briefe und Aufzeichnungen aus der Haft* (München: Kaiser Verlag, 1951).

[3] Deborah R. Barnbaum, *The Ethics of Autism: Among Them, but Not of Them* (Bloomington, IN: Indiana University Press, 2008). I have benefited enormously from the reflections of Barnbaum in this very interesting, if somewhat controversial, book. For a broader discussion of the ethics of autism, see the monographic issue of *Medicine, Health Care, and Philosophy* 15 (2012).

[4] The principles of autonomy and non-maleficence are central to a common morality theory, such as the one developed by Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 7th edition (New York: Oxford University Press, 2013). Here, I use the terms in their more obvious meaning, without necessarily buying into the premises of a common morality framework.

[5] The issue is particularly complicated when it comes to genetic testing in children. Most professional groups and many authors recommend caution. See, for an example, the position taken by the American Society of Human Genetics and the American College of Medical Genetics: "Points to Consider: Ethical, Legal, and Psychosocial Implications of Genetic Testing in Children and Adolescents," in *American Journal of Genetics* 57 (1995): 1233-41. Also, Ellen Clayton, "Genetic Testing in Children," in *Journal of Medicine and Philosophy* 22 (1997): 233-51; Dena Davis, "Genetic Dilemmas and the Child's Right to an Open Future," in *Hastings Center Report* 27 [March-April] (1997): 7-15.

[6] For ethical concerns about employers or insurers using genetic information in a harmful way, see Karen Rothenberg et al., "Genetic Information and the Workplace: Legislative Approaches and Policy Challenge," in *Science* 275 (1997): 1755-57; Lawrence Gostin, "Genetic Privacy," in *Journal of Law, Medicine & Ethics* 23 (1995): 320-330; idem, "Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers," in *American Journal of Law and Medicine* 17 (1991): 109-44; and Nancy Kass, "Insurance for the Insurers: The Use of Genetic Tests," *Hastings Center Report* 22 (1992): 6-11. A big step in

the protection of people from the misuse of genetic information occurred when, in May 2008, President George W. Bush signed the *Genetic Information Nondiscrimination Act* (GINA), making it illegal for employers and health insurers to discriminate against people on the basis of their genetic information. Non-discrimination provisions in the 2010 *Patient Protection and Affordable Care Act* (so called “Obama Care”) build on the same premises.

[7] Uta Frith and Francesca Happe’, “Theory of Mind and Self-Consciousness: What Is It Like to be Autistic?” in *Mind & Language* 14/1 (1999): 1-22. Also Deborah R. Barnbaum, *The Ethics of Autism*, op. cit., 22-23: “The Sally-Anne test and the Smarties test examine the ability that subjects have to recognize first-order false beliefs – the fact that someone holds a false belief. Even those subjects with autism who are able to recognize first-order false beliefs – between 20 and 35 percent of children with autism are able to do so – have tremendous difficulties with second-order beliefs” (ibidem, at 23.)

[8] It must be underlined that these categories are open to a broad range of interpretations by the local Institutional Review Board reviewing the research proposals. One of the central issues concerns informed consent for research on children. Parents or guardians normally give informed consent for medical intervention on children, unless the child is an emancipated minor. Informed consent given on behalf of people without decision-making capacity normally follows the so called best interest standard. Problems with the applicability of such standards in the case of persons with autism are discussed later on, in this paper.

[9] For a general treatment of the issue of surrogate decision making for incompetent subjects see Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, op. cit., 226-229. A classic, unsurpassed, text on the topic remains Allen Buchanan and Dan W. Brock, *Deciding for Others: The Ethics of Surrogate Decision Making* (New York: Cambridge University Press, 1990).

[10] See Ruth R. Faden and Tom L. Beauchamp, *A History and Theory of Informed Consent* (New York: Oxford University Press, 1986).

[11] With reference to the Nuremberg Code see Jay Katz, “The Consent Principle of the Nuremberg Code,” in Georg J. Annas and Michael A. Grodin, *The Nazi Doctors and Nuremberg Code: Human Rights in Human Experimentation* (New York: Oxford University Press, 1992), 227-239.

[12] For this line of reasoning, confront the seminal piece by Hans Jonas, “Philosophical Reflections on Human Experimentation,” in *Daedalus* 98/2 (1969): 219-247. For a history of medical experimentation on human subjects, see David J. Rothman, *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making* (New York: Basic Books, 1991) and Jay Katz, *Experimentation with Human Beings* (New York: Russell Sage Foundation, 1972).

[13] The “theory of mind thesis” suggest that “the core deficits found in autism can be explained by the fact that persons with autism are not able to recognize that other persons have minds. To recognize that another person has a mind is to recognize that person as someone who has a mental life independent of your own, with beliefs, preferences, desires, and the whole range of intentional attitudes,” Barnbaum, op. cit., 21.

[14] The literature on the issue in question is immense. For a good bibliographic reconstruction, see Mary Ruof, ed., *Vulnerability, Vulnerable Population, and Policy*, Scope Note 44 (2004), National Reference Center for Bioethics Literature, Georgetown University. From a philosophical and theological perspective, see essays by Alisa Carse, S. Kay Toombs, Richard Zaner, and Therese Lysaught in Carol Taylor and Roberto Dell’Oro, ed. , *Health and Human Flourishing: Religion, Medicine, and Moral Anthropology* (Washington, D.C: Georgetown University Press, 2006). On the specific issue of research with persons with intellectual disabilities, see Celia B. Fisher, “Goodness-of-Fit Ethic for Informed Consent to Research Involving Adults with Mental Retardation and Developmental Disabilities,” in *Mental Retardation and Developmental Disabilities Research Review* 9 (2003): 27-31.

[15] Fisher, op. cit, 29.

[16] Ibidem, 29.

[17] Allen Buchanan and Dan W. Brock, *Deciding for Others*, op. cit., 23.

[18] Ibidem, 24.

[19] For a presentation of the differences in theories that explain human behavior, see chapter 1 of Barnbaum’s *Ethics of Autism*, op. cit. (“A Philosophical Introduction to Autism”), especially 32-39.

[20] Frith and Happe’, “Theory of Mind and Self-Consciousness,” op. cit., 7

[21] On the conceptual dimensions and the normative implications entailed by the distinction, see Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, op. cit., 226-229. Also, but with a different theoretical underpinning, Raymond J. Devettere, *Practical Decision Making in Health Care Ethics: Cases and Concepts*, 3rd edition (Washington, D.C.: Georgetown University Press, 2010, 99-120.

[22] Raymond J. Devettere, *Practical Decision Making*, op. cit., 102.

[23] Ibidem, 103.

[24] World Medical Association, *Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects*, especially Part III (“Non-Therapeutic Biomedical Research Involving Human Subjects (Non-clinical Biomedical Research), in Albert R. Jonsen, Robert M. Veatch, and Leroy Walters, ed., *Source Book in Bioethics: A Documentary History* (Washington, D.C.: Georgetown University Press, 1998), 13-15.

[25] See the documentation on research involving children in *Source Book in Bioethics*, op. cit., 40-53.

[26] The question invests the presumption of a therapeutic outcome for so called “therapeutic research,” which, logically, cannot be maintained if a *research* hypothesis is still to be demonstrated. Were this not the case, we wouldn’t be talking about research in the first place. Thus, the term *therapeutic* research, and the subsequent distinction between “therapeutic” and “non-therapeutic” research might induce “therapeutic misconception” with regard to the outcome of the firs type of research. This constitutes a form of implicit coercion into a particular research with the allure of a cure, one that clearly affects the purity of informed consent. On the issue, see Paul Applebaum et al., “False Hopes and Best Data: Consent to Research and the Therapeutic Misconception,” in *Hastings Center Report* 17 [March-April] (1987): 20-24. More recently, and as a response to criticism, Paul Applebaum and Charles Lidz, “Re-evaluating the Therapeutic Misconception: Response to Miller and Joffe,” in *Kennedy Institute of Ethics Journal* 16 (2006): 367-73.

[27] See Barnbaum, op. cit., 196-204.

[28] Paul Ricoeur, *Oneself as Another*, transl. by Kathleen Blamey (Chicago: Chicago University Press, 1992).

[29] Barnbaum, op. cit, 199.

[30] Barry F. Brown, “Proxy Consent for Research on the Incompetent Elderly,” in Thomas A Mappes and David DeGrazia, ed., *Biomedical Ethics*, 6th edition (New York: McGraw-Hill, 2006), 240-247

[31] Richard McCormick, “Sharing in Sociality: Children and Experimentation,” in idem, *How Brave A New World? Dilemmas in Bioethics* (Washington, D.C.: Georgetown University Press, 1985), 87-98, at 90. For Paul Ramsey’s criticism of all research on minors, see “The Enforcement of Morals: Nontherapeutic Research on Children,” in *Hastings Center Report* 6 [August] (1976): 21-30. McCormick’s critique of Ramsey is based on a charge of “personal isolationism”: “At the root of our disagreement, then, may be what I would suggest is Ramsey’s narrowly individualistic notion of human nature” (ibidem, 91).

[32] Brown, “Proxy Consent for Research,” op. cit., 244.

[33] Barnbaum, op. cit., 201.

[34] See Vilayanur S. Ramachandran and Lindsay M. Oberman, “Broken Mirrors: A Theory of Autism,” in *Scientific American* (November 2006)

[35] For a discussion of the philosophical premises of these different theories, see the reconstruction in Barnbaum’s, *Ethics of Autism*, chapter 2 (The Value of an Autistic Life), 71-104. Of the works she references, consider, at least, the following: Martha Nussbaum, “Human Capabilities, Female Human Beings,” in Martha Nussbaum and Jonathan Glover, ed., *Women, Culture, and Development* (New York: Oxford University Press, 1995), 61-104, and Thomas M. Scanlon, *What We Owe to Each Other* (Cambridge, MA: Harvard University Press, 1998).

[36] For an assessment of the notion of autistic integrity, see the instructive article by R. Eric Barnes and Helen McCabe, “Should We Welcome a Cure for Autism? A Survey of the Arguments,” in *Medicine, Health Care, and Philosophy* 15 (2012): 255-269.

[37] Francesca Happe’, “Parts and Wholes, Meaning and Minds: Central Coherence and Its Relation to Theory of Mind,” in Simon Baron-Cohen et al., ed., *Understanding Other Minds: Perspectives from Developmental Cognitive Neuroscience*, 2nd edition (New York: Oxford University Press, 2000), 205. Also Francesca Happe’ and Uta Frith, “The Weak Central Coherence Account: Detail-Focused Cognitive Style in Autistic Spectrum Disorders,’ in *Journal of Autism and Developmental Disorders* 36/1 (2006): 5-25.

[38] Thus I find the critique of autistic integrity by Barnes and McCabe, centering on liberty rather justice, not quite to the point: “…evidence for bad consequences of curing adults is simply not strong enough to justify a limitation of liberty,” in “Should We Welcome a Cure for Autism?” op. cit., 259.

[39] This argument is, of course, more than just that, *an* argument. It presupposes a metaphysical trust, whose theoretical presuppositions can at best be alluded to, in a kind of phenomenological gesture. What is being sought here is a phenomenological faithfulness to the evidence of things (*zurück zu den Sachen selbst*!), rather than a logical demonstration based on syllogistic reasoning. In this, I have been deeply influenced by the work of Leuven philosopher William Desmond, especially his *Being and the Between* (Albany, NY: SUNY Press, 1995).

[40] What is being presupposed here is a specific notion of embodiment. For a development of the theme, which can be taken for granted here, see Roberto Dell’Oro, “Embodiment as Saturated Phenomenon: Medicine, Theology, and Some Metaphysical Premises of Modernity,” in *International Journal of Philosophy and Theology*, vol. 2, n. 4 (2014): 69-84

5. The Contribution of Art, Religion and Communication to the 'Treatment' of People with Autism Spectrum Disorders

DR. MARINA NORSI
Former Director
of the Centre for Diagnosis
and Rehabilitation
of Child Neuropsychiatry
at the Beer Sheba Hospital,
Israel;
Consultant in Child
neuropsychiatry
at Villa Santa Maria,
Tavernerio, Como, Italy

In recent years, throughout the world, an increase has been observed in the incidence of autism. In Israel, as well, the data confirm this phenomenon. The incidence of autism in Israel in the year 2014 was 1:83. The total number of cases of autism in Israel in the year 2014 was 7,344.

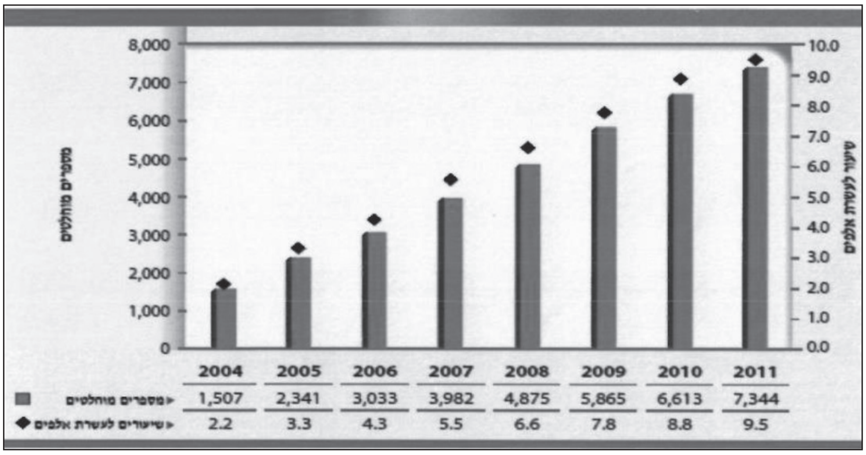
Two observations should be made about these data: 1. The numbers refer to the total population and not to the minorities; 2. In 2004, 98% of the diagnosed cases were in the Jewish population. 'Were Arab children immune to autism? Unfortunately not!' This was simply a phenomenon that was due to a lack of sensitisation to the problem and also to reticence on the part of families in exposing their children to experts. Today the incidence in the Arab minorities is 1:83, the same level as amongst the Jews. However, there is a problem as regards the lack of standardised diagnostic instruments for autism in Arabic.

Specific factors that influence the increase in the diagnoses of autism in Israel:

1. The structure of the national health system which allows early diagnosis and therapy because it is based upon consultants, family paediatricians, paediatricians who are specialised in development medicine, and centres for multidisciplinary diagnosis. The diagnostic process and the subsequent therapy take place in what are short periods of time.

2. In the year 2001 a law was passed which allowed the opening throughout the country of rehabilitation nursery schools for autistic children of 1-6 years old. The opening of these institutions has fostered early diagnosis and therapy.

Tab. 1 Number of patients with autism registered with the Ministry of Welfare in Israel.



	2004	2005	2006	2007	2008	2009	2010	2011
▨ מספרים מוחלטים	1,507	2,341	3,033	3,982	4,875	5,865	6,613	7,344
◆ שיעורים לעשרת אלפים	2.2	3.3	4.3	5.5	6.6	7.8	8.8	9.5

What is the contribution of art and religion in the treatment of people with autism. Is this contribution positive, indifferent or negative?

The influence of religion in addressing the treatment of autistic children: depends on: 1. the strategies that are used by the parents; 2. the resources in the family environment; and 3. support from the external environment: a. therapeutic institutions; b. religious organisations; c. the sensitivity of ministers of worship.

The influence of religion can be:

1. *Positive*:

a. The illness is an expression of higher divine will.

b. The illness offers the parents an opportunity for spiritual exploration and a drawing near to religion.

c. The illness is a 'divine gift' and should be accepted in a positive way.

d. God has chosen us for a very special and elevated task.

2. *Negative*:

a. God does not help us.

b. The illness is a divine punishment because of the parents' doubts about God.

c. The parents react by drawing away from religion.

The reaction of the parents is different in these two groups. In the group where there is a positive influence of religion one encounters a greater capacity to react to stress and a strengthening of the level of religiosity. In the group where the influence of religion is negative one encounters an aggravation of the state of anxiety and a distancing from religious practices. At a general level, the support of religious organisations is of great help for the parents and decreases their stress and their state of anxiety, but in certain special situations it can provoke an opposite effect by creating situations which are difficult to deal with by the parents (for example the inability of the autistic child to be present at the religious functions and a part of the family unit being obliged to stay at home in order to look after that child).

- The observation of a part of the precepts of daily routine (blessings and prayers before and after meals).
- A diet that follows the dietary rules (the separation of milk from meat).
- The decoration of the environment without symbols and figures that are not acceptable.

Table 2. Statistical data on the population in Israel on the basis of religion *The total population in Israel in the year 2014 was 8,180,000*

Population	Total	Percentage
Jews	6,135,000	75%
Arabs and Druze	1,694,000	21%
Others	351,000	4%

Sub-division of the population on the basis of religion and levels of religiosity

Religion	Level of religiosity	Percentage
Jews	Atheists	43%
	Orthodox	9%
	Religious observers	23%
	Partially religious observers *	25%
Arabs	Muslims	83%
	Christians	9%
	Druze	8%

** Follow traditions but do not practise all the precepts*

The Contribution of Religion in the Treatment of Autism in Israel

Question: ‘Does the level of religiosity of families influence the trends, the contents of therapy and the decisions as regards the specific methods of therapy?’

Until the 1990s in the world of orthodox Jewish families ‘special’ children were for the most part segregated within the family in order to protect the other members of the family as regards future marriages. Since 1990 there has been a drastic change, namely the opening of the first institutions (nursery schools, schools) within an educational-therapeutic framework. At the present time, autistic children from orthodox Jewish families are placed in special institutions that are able to meet the requests of the parents:

- Respect for Jewish feast days and events.
- The maintenance by teachers of appropriate dress.
- Separate classes for boys and girls above the age of twelve with teachers of the same sex.

Exceptions to the rules: where there is an absence of suitable institutions, the parents are able to engage in compromises for the good of their children.

In Muslim families the religious factor is seen as a factor of great importance for parents but it has less impact in the choice of therapeutic institutions for their children.

Personally, after over thirty years’ experience with nursery schools for Jewish and Bedouin children I feel deep dilemmas in exposing children of Arab culture to Israeli norms.

Art Therapy

This began in the 1960s in London as a psychiatric therapy with very specific objectives in the field of psychotherapy. With the passing of the years, the use of art therapy has expanded and it now forms a part of, and overlaps with, other traditional therapeutic fields.

Art Therapy in Autism

This is a seen as a complementary therapy together with other therapies such as music, play, water therapy and horse therapy. It does not take the place of conventional therapies. It is not always included in educational and therapy programmes. In Israel, it is included by law in all educational institutions providing therapy and is implemented both by formal professionals and by teachers in cooperation with formal professionals and professionals of occupational therapy.

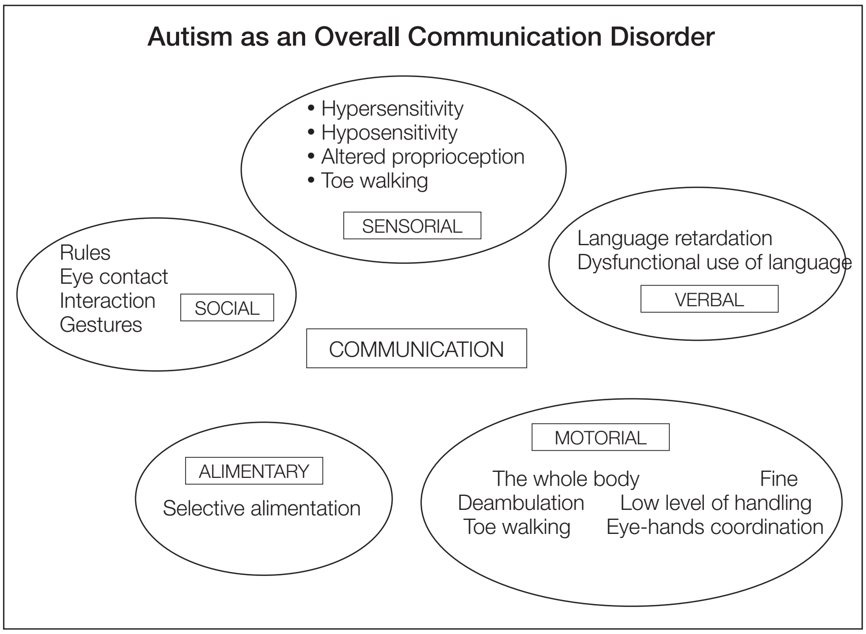
The Advantages of Art Therapy

1. It is a non-verbal means of communication.
2. It is accepted by children in a positive and non-threatening way.
3. It strengthens eye contact.
4. It strengthens recognition and the learning of colours, geometrical forms and objects.
5. It allows contact with various materials and textures.
6. It strengthens fine motor skills.
7. It develops the imagination and the capacity for abstract concepts.
8. It allows the child to acquire notions in a pleasant way.
9. It is a valuable means for the external expression of concealed artistic abilities.
10. It is an instrument for cooperation between children and between children and adults.

In Israel in rehabilitation nursery schools fourteen hours a week are dedicated to complementary therapies, amongst which there is art therapy in addition to conventional therapies. Despite the fact that art therapy is recognised in many parts of the world as a therapy of great value, data have to be provided in a quantitative way in order to be able to expand the field of research and confirm its efficacy.

I will now describe to you the 'integrated' model which, in being based on a holistic approach to the autistic child, allows the use of art therapy and religion as valuable instruments by which to address the complicated set of symptoms of autism.

This model is based upon the concept of an 'overall communication disorder' which sees the whole set of symptoms of autistic children as an expression of a communication deficit in the various fields of their growth and development.


Autism as an Overall Communication Disorder

Examples of How to Use Complementary Therapies	
Art Therapy	
SYMPTOM	CONTRIBUTION OF THE THERAPY
1. Speech retardation	Use of pictures to strengthen communication and speech
2. Low or absent eye contact	Strengthening of eye contact with fading in-fading out
3. Hyposensitivity	Handling of various materials and textures
4. Low fine motor skills	Construction of 'objects' with various materials - Strengthening of bimanual coordination
Religious Practices	
SYMPTOM	CONTRIBUTION OF THE THERAPY
1. Speech retardation	Shortened and repetitive daily prayers
2. Low fine motor skills	Washing of hands before meals and inherent blessing (contact with water, bimanual motor skills)
3. Socialisation	Periodic religious activity
4. Alimentation	Tasting foods typical of various Jewish events
5. Overall motor skills	Getting up and sitting down during prayers

Conclusions

The complementary therapies constitute a valuable alternative therapeutic instrument in the 'treatment' of autism. The contents of these therapies are in general well accepted by autistic children and are seen by parents as non-threatening therapies given that they are also used as collateral activities in children with normal growth and development.

I thank you for listening to me and I take my leave with a word of vital importance for Israel: PEACE.

FIFTH SESSION

PSYCHO-SOCIAL, CULTURAL, EDUCATIONAL, THEOLOGICAL AND PASTORAL ASPECTS

1. ROUND TABLE

The Contribution of the Various Figures Involved in the Accompanying and Education of People with Autism Spectrum disorders

1.1 Parents

DR. FRANCESCA MALAFFO
DR. MAURIZIO BRIGHENTI
DR. ANNA FRANCO
DR. FEDERICA BIANCO
DR. MELCHIORI LUCIA
DR. FEDERICA OPPI
DR. SARA STEVAN
The Centre for Autism
Diagnosis, Treatment
and Research
ULSS 20, Verona,
Italy

The Centre for Autism Diagnosis, Treatment and Research of the ULSS 20 in Verona which since 1997 has addressed itself to autism, the identification of autism in an increasingly early age, and research into, and the rehabilitation of, individuals with autism, seeks to understand and offer support for the problems that this disorder involves, bearing in mind the various contexts that exist, and especially the context of the family.

Down human history thinking about the origins of this pathology has followed a continuum from a reading of a relational character to one of a neurological basis, and then from its attribution to maternal responsibility (refrigerator mothers) to its attribution to genetic and environmental failings.

The most recent theories have highlighted a failing of the various neuro-psychological functions, with the identification of a 'disconnected' functioning of the brain.

We have thus witnessed a diagnostic evolution as regards the aetiopathogenesis of autism which is treated as a pervasive disorder that is not the result of an environmental context or neglect by the mother, as it was defined at the outset, but as an epigenetic phenomenon in which environmental and genetic factors influence a neuro-atypical development and lead to an observed clinical disorder. This is a fundamental shift – the idea of a refrigerator mother, in addition to blaming mothers, unleashed a great sense of guilt on them and produced grave consequences in the family context.

In the light of all these difficulties that characterise the first stages of life of an autistic child, the health-workers involved in the diagnosis often witness difficulties in the relationship between the child and the primary figures of his or her affective reference, but these, in the case of autism, are secondary to the presence of such a disorder.

One is dealing with states of anxiety in parents connected to the difficulty that is encountered in identifying the causes of the pathology and incomprehension as regards the behaviour of the child who seems not to interact with them and who seems not to enjoy the primary maternal relationship.

When the family has access to our centre, the specialist often finds himself or herself in front of family contexts where the relationship between the parents and the child is distorted. The moment of the diagnosis of autism further affects this already existing frailty. Whether one is dealing with early autism or secondary autism, as some authors tend to specify when reference is made to the beginnings of the pathology the family at the moment of the diagnosis is already experiencing a relational imbalance.

When we speak about autism we cannot simply refer to this kind of handicap as the subject of assistance therapy – we are also forced to consider all the dynamics related to intra-family and extra-family relationships because one is dealing here with children. Thus we would like to consider in today's paper handicap as an event that unleashes reactions and counter-reactions in the child and in his or her family network: the family and all its components are influenced by the event of the disability of a child and are forced to engage in a reorganisation.

The moment of the diagnosis is highly incisive in the life cycle of the family because it is a critical event that freezes the normal evolution of the family. Usually, a diagnosis of autism takes place for the most part during the pre-school stage, a stage when the existential project of the parents enters a state of crisis because they feel that they are the parents of a child who is not healthy and, where there are other children in the family, they also feel responsible for them.

The communication of a diagnosis of autism creates different effects on the family depending on whether the autism of the child is early or regressive. In the case of early autism and thus of a lack of development of certain capacities of the child from the first months of life, at the moment of diagnosis the family system is usually already alerted. Indeed, the parents often relate that they have been anxious for some time because of difficulties that are already evident. In this case the relationship of the child with the mother, which is of fundamental importance for the psycho-physical development of the child during the first months of his or her life, is obstructed by the inability of the mother to understand the child's needs. We witness, in fact, unexpected forms of behaviour of the child within the exchange with the mother: the child does not look straight into the eyes of his or her mother often from the first stages of interaction with her, for example breastfeeding; the child does not turn round when his or her mother calls him or her; and the child may call for help through a constant and inconsolable crying or is not able to ask for help. This leads the parent not to understand what the child needs, unleashing a sort of anxiety about the maternal performance in which the adult of reference, not knowing how to manage the help-providing situations, runs the risk of losing her role of care which usually makes her vital for the child.

In the case of regressive autism, that is to say a loss of abilities after an initial normal development, the parents find that they have to address an unexpected and sudden situation because the child until that moment was a healthy child and his or her relationship with his or her mother was an adequate relationship. In this case, however, the acceptance of the diagnosis could require more time and more energy because it is a critical event, a sudden event, an event which characterised by the loss of the image of the child as a healthy child.

The acceptance of a diagnosis of disability is one of the most complex processes of the human mind. The parents have to draw up a new parental role within the relationship with their child. This is a re-arrangement of affective processes, of the forms of care and upbringing, that the parents find that they have to address when they have before them a child with autism, and they must, therefore, be accompanied on this pathway of suffering in order to be able to restore a relationship both with their children and as a couple.

The reactions of parents when they are faced with a diagnosis of autism can take many forms and depend on the resources of the relationship of the couple before the event of disability; on the resources of the personalities of them both and thus on the capacity to react to a traumatic situation; but also on the kind of tie that exists between the members of the family. Sometimes one can observe a capacity on the part of the family to evolve in a maturing sense; in other cases one witnesses families that are not able to react in an equally balanced way and implement defence mechanisms such as denial or seeing the handicap of the child in a distorted way and attributing the difficulties, for example, to laziness, contrariness or mistaken forms of education. These mechanisms of denial have the effect not only of rejecting the difficulties of the child but also of not recognising his or her capacity to develop.

Which factors predispose to a better acceptance of the diagnosis and a more useful reorganisation of the family? Thus which factors help these parents?

Various components have to be considered. The first concerns the individual resources of the parents. Second, the families to which the parents belong who can play an important role not so much as affective replacements as supporters of the new family organisation. And lastly, the rehabilitative institution: its presence calms the parents who up to that point feel lost and confused about the most suitable forms of upbringing and education to engage in and they also feel alone because of the absence of support and understanding.

The rehabilitative institution has the task of proposing and supporting the rehabilitation project for the child and of maintaining links of attachment between the parents and their child, which are of fundamental importance for the good, albeit partial, development of the child. Offering a rehabilitation initiative for the child can have the effect of alleviating the anxiety of the parents and thus of the child as well – it constitutes an active way of tackling disability.

Anxiety, indeed, is a component that has been amply analysed within the relationship of parents with an autistic child. The literature in the field reveals how within these families there is an experience of powerlessness and inadequateness felt by the parents in not managing to understand the requests of the children because, in the presence of a capacity for language as well, it is used in a way that is often not congruent and communicative.

The difficulties emerge when

all the institutional agencies, the school in particular and the rehabilitation centres, end their tasks with the child who by now has become an adult: the family goes back to feeling alone in its own reality without having adequate reference points for the child.

For these reasons it is important for the associations of parents and the institutional agencies that are present in the local area to try to find resources to foster a social inclusion which for years the parents have tried to maintain in the school and the life environment but which runs the risk of disappearing completely during adulthood or after their deaths.

To end this paper, good personal resources of the parents, a harmonious family environment; the support by the families of the parents; the cooperation of institutional agencies; the involvement of the parents in rehabilitation in a special institution which can point to an individualised therapeutic project for the child; and understanding the difficulties of the family and supporting it, often involve a reorganisation of the family which is more balanced: this is a factor that facilitates a good clinical development of the case, above all at the level of the behaviour of the autistic child.

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1.2 Educators

PROF. CARLO HANAU
Lecturer in Medical Statistics
and the Planning and
Organisation of Social
and Health-care Services,
the Department of Education
and Human Sciences,
the University of Modena
and Reggio Emilia,
Italy

Through education we provide hope. However, we do not sell illusions. We do not imitate charlatans who sell what has not even been tested as an effective medicine or even sell what has already been counterfeited.

For children and people with autism what the National Autistic Society and Autism Europe stated many years ago still, unfortunately, applies: the treatment is education. This situation is a consequence of the fact that medicine at the present state of knowledge has little or nothing to offer to people with autism, despite the documented biological basis of this grave disability. Indeed, medical products can do very little as regards the hard core of this syndrome and often their side effects, where there is a prolonged use of them, reduce the quality of life of those who use them a great deal. Pharmacological research of the future is the hope whereas today individuals with autism can benefit from special personal education and from the specific arrangements of their environments during their life spans. The responsibility, therefore, of the educators towards them is great and such educators must prepare a child with autism for adult life and follow him or her in a continuous way.

Let us establish what children with autism need: parents and the other family members, nursery school teachers, support and curriculum teachers, pedagogic coordinators, psycho-pedagogues, social and professional educators, assistants as regards autonomy and communication, and, lastly, their companions, and this with a view to cooperative education. To flank these there are the health-care workers with whom close cooperation is required, without, however, turning education into health care.

Parents have the task of bringing up their children, and to them our Constitution of 1947 delegates to them this right and duty, rejecting the hypothesis of a totalitarian ethical State (Art. 30: it is the duty and the right of parents to maintain, instruct and bring up their children, even if born our of wedlock. Where parents are incapable of doing this, the law envisages that they are absolved of their tasks). This provision must apply to all children, including those with autism spectrum disorders, for whom is added the UN Convention on the Rights of the Disabled, which was ratified by Italy at the beginning of 2009, and the motto 'Nothing to us without us' of the associations for disabled people. One should, however, make clear that the parents of these children who have very special problems are not technically prepared for them and have to learn to be special parents in order to organise the lives of all the members of the family in those ways that are most suited to the special needs of these children. Informed and instructed parents thus have the task of cooperating in education in subsidiarity with educators and even more in the choice of educational goals and the pedagogic methods to be employed, on a par with what happens with the provision of informed agreement in health-care treatment.[1] One must assure to the parents clear and understandable information regarding possible alternative strategies which have been demonstrated to be effective and the respective health-care results that are expected, instructing them in cooperating at the educational level that is chosen by them. Their choice, in order to be rational and also sustainable on the part of the state agency, should take place within guideline n. 21 of the Higher Institute of Health Care which was published in December 2011. When analysing the whole of the international scientific literature in the field, this laid down in relation to education that 'intensive behavioural programmes are also effective'; 'amongst these programmes the most studied are those based upon applied behaviour analysis (ABA) (http://www.snlg-iss.it/cms/files/scheda_autismo_14-03.pdf). By 'intensive programmes' is meant those programmes that require from a minimum of 25 to a maximum of 40 hours a week. The free work of parents, if suitably instructed and supervised, can contribute to reducing this heavy care workload',[2] which is made necessary by the typical difficulty of generalising good behaviour learnt in one setting to all the other life environments.

Actions of special education which have hitherto been acknowledged as valid involve a notable cost of human resources of a non-remunerated kind (parents and other family relatives) and remunerated kind, as in the case of educators, which if they are not offered at public expense run the risk of ruining the family's budget. The training of parents is thus necessary and the related costs can be seen as a convenient investment because they reduce current public expenditure and even more future public expenditure. One can estimate the cost of the life of a person with grave autism as 2-3 million euros, whereas intensive education, by reducing the gravity of the situation, allows great savings in terms of expenditure on public assistance, above all during the 'after us' stage.

Information and then instruction and supervision must be accessible to all these parents, even to those who are less educated, because children with autism are born in all countries and to parents from all social classes, all levels of instruction, and all professional categories.[3] This widespread presence of autism contradicts the psycho-genetic theory which pointed to an inadequacy of maternal love (the refrigerator mother) as the cause of this syndrome.[4] Falling into a gigantic statistical error, Kanner, from whom, indeed, this syndrome took its name, for a part of his career believed that he could affirm that this syndrome was confined to families of a high social level and thus that it was provoked by the inadequacy of maternal love. Many psychodynamic and Lacanian psychoanalysts, and others such as Bruno Bettelheim, who passed himself off as a psychoanalyst, used this as a reason to propose 'parentectomy', that is to say the separation of the children from their parents as a form of initial treatment.

Even though half a century has passed since Kanner (1969) acknowledged his error, many followers of Bettelheim have continued to treat children with autism as though the cause of the disturbance was their relationship with their mothers. These followers are still very present and active in countries with Latin-based languages – France, Belgium, Switzerland and Italy, where often a public worker seeks to apply to his educational choices the principle of '*cuius regio eius religio*', imposing on parents the choice made by that public worker.[5]

Apart from the pioneering experience of Asperger, who well understood the utility of special education in autism and applied it with his nuns in Austria during the Second World War, Lovaas was one of the first to address these children who were ar at that time defined as 'uneducable', applying to two- or three-year-old children with autism a strategy based on the ABA in an intensive way (forty hours every week) and also a strategy that was individually applied (a one-to-one relationship), obtaining the first good quantifiable and quantified improvements. Indeed, the ABA teaches an establishment of the objectives of education and the measurement of its results in an ongoing way, differently from the psychodynamic and Lacanian approaches. Lovaas also required a strong special educational commitment from at least one parent.

In parallel, Schopler dedicated himself more to the spectrum of upper age bands and drew up and implemented the state programme for North Carolina which was called T.E.A.C.C.H.[6] He paid greater attention to the organisation of life environments for the whole of a person's life. His definition of the parents as 'co-therapists' in the enabling of their children indicates how nuanced is the boundary between health care and upbringing, which in the case of autism is the only form of 'therapy' , but above all it should remind us that a generalisation of learning of any ability, which is a difficulty typical of autism, requires the expert educators to move in perfect harmony with the family so that that the ability to do the buttons of a jacket is taught in the morning at school and then repeated in the evening at home. In addition, Schopler, who privileged the Italian Montessori as a methodological reference point, wrote that many of the activities proposed by his T.E.A.C.C.H. derived from positive direct experiences of parents of autistic children.

It seems superfluous to observe that a choir with one voice of all those who take part in the education of children is always to be welcomed. However, in the case of autism this coordination is absolutely necessary. To this end, parent and teacher training has spread and here the training is common to both parents and professionals. In addition, during the course of educational activity the expert educator who draws up a life project and follows its implementation, indeed the person who is the true conductor of the choir, goes both to the school and to the home of the child in order to test whether the strategy that has been drawn up is being correctly applied and to also provide advice.

This specialisation of the parents cannot and must not become their professionalization, something which works against the natural character of their fundamental parental and conjugal role. This risk emerges when the school and health-care systems are not of a sufficient level to provide quality responses to a person with autism, as unfortunately generally takes place in our country. Thus the percentage of separations and divorces in families which have a child with autism is much higher than in other cases of disability, even where these are grave. [7]

In Italy we have had the paradox of a large mass of human resources allocated to pupils with disabilities, indeed over a hundred thousand support teachers, to whom should be added the educators of local councils, the assistants for autonomy and communication of the provincial councils, for over two hundred thousand pupils who have certificates of disability. For pupils with autism on average a relationship of one to one with the professional is allowed. This abundance of personnel, which is unknown in other countries, allows the inclusion of just one pupil with a disability in an ordinary class in the place of special classes that are very widespread elsewhere where a small group of 4-6 pupils with autism is placed in one class under an expert educator and one assistant within an ordinary school that allows the inclusion of pupils with autism amongst the other pupils only for some school activities, meals and recreation. In the United States of America there have been some recent good examples of classes made up of pupils with autism and other non-disabled pupils. In Italy the achievement of the inclusion in ordinary classes that was codified by the Falcucci law n. 517 of 1977 can be criticised because of the poor results obtained after schooling: the total inclusion pointed to for the years of schooling ends brusquely and these young people are directed to day centres for disabled people and type 'B' social cooperatives. Very few young people with autism manage to enter the world of normal work, indeed less than those who manage to do this in countries with special classes.[8]

The Italian paradoxes that have just been described call on my professionalism as regards the planning for social and health-care services. The efficacy (results in terms of improvement) and even more the efficiency (the relationship between the results obtained and the means employed to obtain them) of the system of education of people with autism spectrum disorders are both very low. These are inefficiencies whose causes should be eliminated, namely the low or absent specialisation of the training of teachers as regards the autism syndrome and suitable strategies for combating it, in particular those based upon the ABA, which, indeed, was rejected by our country in the 1960s. One may also refer to the turnover of support teachers which is in contrast with the need for continuity and the accumulation of experience; a lack of supervision; and a lack in many regions of the figure of the assistant for autonomy and communication who, instead, should be given to all cases of autism where there are grave difficulties of communication, which are, indeed, often even greater than is the case with deaf and blind people who, differently from people with autism, habitually receive this kind of help in all the regions of the country.

Theoretically, for over five years, with the agreement signed by the Minister for Instruction Fioroni,[9] networks of schools should have been created with at their centre a pole school for a given kind of disability – not to attract all the pupils with that disability to the same pole school but to create within it a team of specialised teachers, with the teaching chair in the pole school, who are ready to assure their constant presence in the other schools of the network where a pupil with that disability enrols, although maintaining strong relations with the other colleagues of the team. The non-application of this law is an indicator of the difficulties that exist as regards changing the apparatus of state schools.

The guidelines on autism of the Unified Conference (Ministry of Health, Ministry of Instruction (MIUR), regional, provincial and local councils), which was approved in 22 November 2012, sought to remedy some of the grave failings registered in all the sectors that should act in an integrated way in relation to autism, for all ages, but whose application has been limited to a few regions such as the Marches and Sardinia. In the rest of Italy there continue to be delays in the diagnosis of autism and after such a diagnosis there is a waiting list of months or years before the initiatives that are needed are taken. It is expected that the Senate will soon approve a unified text of various specific Bills that will establish Essential Assistance Levels (EAL) as a guarantee for minimum effective action for all people with autism of all ages, independently of the regions where they live.

A Bill has been introduced into the Chamber of Deputies which is the outcome of an agreement of 2014 between the Ministry of Instruction, the Federation of National Associations for the Disabled, and the Italian Federation for the Overcoming of Handicap: ‘The Bill to improve the quality of school inclusion’. This should give greater continuity and a specific training to teachers and their integration with other educators and families. These laws, if they are approved, could assure the elimination of the current waste of human and material resources, which causes irreparable damage to people with disabilities, their families, and the public treasury which is forced to pay out, as has been already observed in this paper, two to three million euros to assist each person who has grave autism.

These two Bills are needed to save schools for everyone as intended by the Falcucci law and to obtain the real inclusion of pupils with autism in ordinary classes, which would otherwise be condemned to failure because of its own inefficiency.[10]

To end this paper, in order to safeguard the inclusion of pupils with autism in ordinary classes a diagnosis, albeit a provisional one, should be carried out as soon as possible, and action should be taken immediately so that the entrance of such pupils into elementary schools is prepared for in a suitable way, avoiding this placing of such children becoming a grave problem for themselves and for their classmates. In addition, there should be an increase in the number of educators who are specialised in autism, assistants in autonomy and communication should be widespread, and emphasis should be placed on the consultant-coordinator-supervisor of the project for the child, who should, indeed, have personalised help and one that undergoes constant development with accompanying hoped-for improvements. A person with autism must conserve the diagnosis and his or her specific treatment which must last, in a no longer intensive form as well, and in adult life, in shared environments and in homes where specialised workers should be present.

Notes

[1] Only a magistrate can intervene to deprive parents of their power when they follow pathways that could injure their children but on the whole the power of parents applies.

[2] Sally Rogers has recently published a preliminary study (*‘Autism Treatment in the First Year of Life: A Pilot Study of Infant Start, a Parent-Implemented Intervention for Symptomatic Infants, S. J. Rogers • L. Vismara • A. L. Wagner • C. McCormick • G. Young • S. Ozonoff, J Autism Dev Disord, DOI 10.1007/s10803-014-2202-y,* published online on 12 September 2014) where a group of children between the ages of 7 and 18 months, who displayed symptoms of autism, were treated by their parents, who had been trained through parent training and with a supervision at home for one hour a week for 12 or 16 consecutive weeks. The first results, albeit not very great, are very encouraging. Agreement exists between all experts that the plasticity of the brain of the first years of life allows special education to obtain great improvements at the level of prognosis, which otherwise with its natural development would be very grave, above all for children where the syndrome is manifested early on. The observation of Prof. Gilbert Lelord, a consultant in child neuropsychiatry at Tours, that was made thirty years ago still applies: treatment is required before the definitive diagnosis. It should be recognised that the special education advised by guideline n. 21 of the ISS and the guidelines of other countries not only do not do harm but produce positive effects in false positives.

[3] Only some exceptions are known: the frequency is higher in countries where marriages between relatives are more frequent; thus some American epidemiological colleagues study the diffusion of autism in Arab countries.

[4] Kanner described this syndrome for the first time in 1943 in a scientific review of psychiatry, correctly defining it as innate. Subsequently, after this publication, he received tens of children with the characteristics that he had described who were members of American families of a high educational level – something that had enabled them to learn about the contents of this scientific review and having sufficient money to go to the expensive university hospital in Baltimore where Kanner worked. Taking for granted that the sample of families was representative, Kenner posited that a rich mother with a career, who in his view would have not taken much care of the child, was the cause of this syndrome.

[5] In Italy, in 2012 the psychodynamicists and Lacanians, with the support of the professional associations of psychologists, publicly contested guideline n. 21 of the ISS and asked for its immediate revision because it was too philo-American.

[6] An acronym for ‘Treatment and Education of Autistic and Related Communication Handicapped Children’.

[7] See the survey of the Fondazione Serono and ANGSA onlus, carried out by CENSIS in 2012: http://www.fondazioneserono.org/sezione/disabilita/la-centralita-della-persona/lindagine-sulle-persone-con-autismo-disabilita/

[8] Our present model of inclusion of those who have grave disabilities, such as people with autism, is based on the error that one need only put this kind of pupil next to others for him or her to be included. The lack of effective specialised education has now brought about a failure which is manifested to the full after schooling when the child who has not had the special education that he or she should have had cannot be included in the society of adults who work and has to be placed in a centre together with other gravely disabled people. During the 1970s Enrico Montobbio in Genoa tried to include grave cases in work environments, with the purpose of inclusion rather than production, but the shortage of special education able to reduce problem behaviour of people with autism made this optimal solution very difficult. The failure of our special education is also manifested in secondary schools where one witnesses a concentration of pupils with autism spectrum disorders in some agrarian and hotel institutes which respond not a little better than others to the specific needs involved. For some years there have been agreements signed in the Provinces for programmes to prepare for work inclusion during the years of schooling. The ‘300 days Project’ of the Regional School Office of Emilia Romagna, which was financed by the Agnelli Foundation and has just come to an end, belonged to this approach: cf. http://www.istruzioneparma.it/2014/05/27/seminario-conclusivo-del-%E2%80%9Cprogetto-dei-300-giorni%E2%80%9D-%E2%80%93-bologna-11-giugno-2014/

The Regional Council of Emilia Romagna approved law n. 7 of 2013 for the application of work placements which also allows the placing in an ordinary job of people with grave disabilities, including people with autism, through the third typology whose function is one of direction and training or placing or reintegration not only in terms of work but also at a social level for people with disabilities and in disadvantaged situations. Cf. http://formazionelavoro.regione.emilia-romagna.it/tirocini

[9] On 20 March 2008 the State-Regions Conference expressed a favourable opinion about the text of an inter-Ministerial decree between the Ministry for Instruction and the Ministry of Health, ‘An agreement for the placing in schools and the taking of responsibility for pupils with disabilities’. However, this has largely not been implemented.

[10] Reference may be made to a part of a policy document of Autism Europe of 2003 which is still of contemporary relevance: ‘For people with autism, education has first of all the role of compensating and if possible overcoming incidental learning and communication difficulties. One of the problems that is encountered as regards this task is that many of the abilities to be taught are so elementary that it is often difficult to see them as subjects for teaching, and the tendency is to take them for granted. In addition, the strategies for teaching them are not simple and require teachers to have in-depth knowledge about autism as well as a good measure of creativity. We cannot rely upon ‘normal’ teaching strategies which do not include the teaching of basic abilities, given that ‘normally endowed’ children, like children with intellectual disabilities without the characteristics of autism, acquire them without any need for teaching – they only observe what others do. This kind of learning does not take place in children with autism, and this is the reason why also in the case of being placed in ‘normal’ schools, teachers should be made available who have specific training as regards the educational aspects of autism in order to support curricular teachers and help with their impact on other children’.

1.3 Socio-Psycho/Health-Care Workers: the Integration of Children with Autism Spectrum Disorders through ICT

MRS. SALOMÉ RECIO CARIDE
Teacher and PhD student
in Pedagogy,
Spain

Special Instruction in the Spanish Educational System

After years and years of decrees, norms, and changes to legislation in the educational field, our country began to consider the basic principles of care for people with disabilities in all sectors and, obviously enough, in that of instruction as well, opening the doors to disabled children in order to offer them the possibility of sharing in the educational process with their contemporaries in normal schools. This is one of greatest advances that has been achieved in our schools.

'People should understand that integration is beneficial for the community and for improvement in schooling. It cannot be seen simply as a problem and a way of treating children with disabilities. Integration does not consist of this but, rather, of creating normal schools that can address all of our children. The fundamental point is that normal state schools, paid for by the citizens, have refused or have been reluctant to accept all children. The problem is not the success or failure of special instruction but the fact that normal schools have not implemented this fundamental obligation. In New Brunswick we have great leadership provided by political personalities of the highest levels, such as the Prime Minister who is currently in office, by the authorities responsible for overseeing matters and by civil servants of a high level in the sector of instruction. There have been schools districts that have made advances, demonstrating that the thing could work, that integration was a reality and not a radical and mad ideal of the Left, but, rather, a normal approach, directed towards the family and common sense' (interview with Gordon Porter).

In Spain the royal decree 334/19851 on the organisation of special instruction marked an important stage because it established that the curriculum of special instruction must be based, whatever the case, on the ordinary, taking, however, individual differences into account. This decree marked the beginning at an experimental level of the Spanish programme of integration and as a consequence in 1986 the National Resource Centre for Special Instruction, under the Ministry for Public Instruction, was brought into being.

In its first article the first overall law on the right to education refers to the right to instruction of everybody: all Spaniards have the right to a basic instruction that will allow them to develop their personalities and to engage in activity that is useful to society. This instruction is obligatory and free at the level of general basic instruction and at other levels established by the law (LOE).

In recent years many advances have been made as regards the quality of instruction in the lives of people, including those individuals who are limited by disability. There have been many successes, even though we have to continue to improve by developing new experiences and involving all those professional workers who have responsibility for students.

When parliament was legislating on the integration of pupils with disabilities, various figures were placed in school centres, such as 'special guides' and specialists in hearing and in therapeutic pedagogy. To these three different figures, together with the tutors of these pupils, is entrusted their integration in these centres.

From that moment onwards it has not been difficult to find in schools pupils with autism spectrum disorders, Down syndrome, Asperger syndrome, TGD, TDG, and blind or dumb children. The integration of all these pupils into normal classes requires attention being paid to functional diversities and the elimination of the current barriers at the level of the curricula which ask pupils to achieve the same objectives, independently of their personal characteristics.

As a consequence, our obligation as teachers is to ensure that the integration of these pupils is as simple as possible, offering all the opportunities of which we are capable in order to achieve their social integration.

The group of the Department for Guidance is made up of the guide who can be a psychologist or a pedagogue and to whom are entrusted in fundamental terms the models of observation and the implementation of ways of working with children who have special educational needs (SENC), in addition to the task of working with the tutor in gathering information on the children, providing material for conversations with their families, or taking part directly in these meetings. He or she has to follow the disabled pupil in order to monitor the advances that have been made during the period that he or she attends school.

The specialist in therapeutic pedagogy is a teacher who is specialised in special instruction and who engages in his or her work as a teacher in centres for the instruction of children at a primary and secondary level. His or her functions are substantially those of attending to and supporting the special educational needs children and of drawing up together with those teachers who are tutors of these pupils an individualised change in their curriculums with a periodic coordination carried out with all these teachers and tutors, in a addition to drawing up of didactic material that is suited to these pupils.

The specialist in hearing and language has to engage in work involving prevention, diagnosis and prognosis, and he or she also has to draw up treatment and assessment for communication disorders, always working in an educational context. He or she can also diagnose and assess, through individual or collective tests, the existence or otherwise of a disorder in the field of language communication, at the same time involving the parents and the teachers, producing tasks and taking part in the specificities of the centre to which he or she has been assigned.

In every classroom at any stage of the educational pathway, the tutors can support the SENC, relying upon these specialists who facilitate the teaching work in order to achieve an effective integration of these children in the ordinary educational centres.

Thanks to the advances that have been achieved, in recent years the question of autism has often been addressed in educational contexts and in other areas of society. The diagnosis of autism has increased notably in recent years. Some research carried out recently has revealed that one child in every ten is diagnosed as having autism and four out of every five of these are males (Autism Society of America, 2009).

For this reason, both the parents and the teachers should have a clear knowledge of this process of the integration of children in order to assure involvement with the social and educational aspects that are taught to these children (Swartz).

In order to facilitate this task for parents and teachers, the health committee of the regional council of Murcia, together with the educational committee, has recently published a book which seeks to be a useful instrument for all those professional workers who are involved in the identification, diagnosis and treatment of autism spectrum disorders. This test is also useful for the families of these children and in this way facilitates learning and development.

The Use of Information and Communication Technologies (ICT) in Integrated Schools

The presence of ICT in society is an evident reality and a field for reflection in constant evolution which has expanded over recent years because of the speed with which technological advances have been taking place and because of their presence in, and impact on, the world of education and training (Selwyn and Gouseti, 2009).

A great effort has been made by managerial groups and education committees in educational centres to introduce all the resources and the instruments of ICT in order to update our institutes in a way that is in line with the epoch we are living in. This use constitutes an indicator of quality and an improvement for the teaching-learning process (Aguaded and Díaz, 2010).

In the case of pupils with special educational needs, technology has offered a decisive contribution because these instruments allow access to activities which would otherwise be not very practicable or even impossible. Technologies can be a suitable solution by which to meet, at the level of teaching, the specific needs of students, and they are thus a powerful teaching tool (Alba, 1998; Pensosi, 2010). However, as Pavia (2010) has observed, interaction with the digital world, amongst other things. increases the opportunities for these pupils to interact with their environments and thereby to increase their quality of affective, personal, emotional, working and professional lives, thereby avoiding their marginalisation and facilitating their integration (Cabero, Córdoba and Fernández, 2007).

In recent years various technological means have been used in schools to promote and stimulate learning in pupils with special educational needs, in general, and in pupils with autism spectrum disorders (ASD), in particular.

In this sense, in order to be able to teach these students, who have grave difficulties in interacting at a social level and in communication, and in the attribution of mental states, that is to say in the comprehension of what others are thinking or feeling, the use of these technologies seems to be a suitable instrument given their characteristics and their educational needs. In reality, many people with autism spectrum disorders seem to have a natural affinity for work with ICT given that they provide a controlled environment, individual attention and the possibility of replicating the activities that are proposed. It has been demonstrated that learning tasks developed in digital and computer environments can motivate and encourage learning in people who have autism spectrum disorders (Cheng and Ye, 2010; Parsons, Leonard and Mitchell, 2006; Pensosi, 2010). It is true that most boys and girls are stimulated by ICT supports but children with autism spectrum disorders can find them even more attractive because of their characteristics in the cognitive management of information, preferably of a visual kind (Lehman, 1998).

As a consequence, the use of computers and ICT programmes is supported by teachers as a useful instrument that can be added to the educational programmes and projects of pupils with autism spectrum disorders as a more integrated element in their process of instruction. This technology thus emerges as a means by which to support these people to help these children in their functional limitations, improving their learning, independence, autonomy and mobility.

Thus I here describe our experience in the use of ICT instruments for the process of the teaching of emotional and social skills for people with autism spectrum disorders.

My Personal Experience with Children

As a teacher who loves my profession and the use of information and communications technologies, I love to create on my own instruments which can be personalised together with the pupils, trying in this way to draw near to their needs. For this reason, I have dedicated myself since 2006 to creating interactive games, with which I want to reach all kinds of children, and in a special way those who have special needs, since the motivation and the stimulation that these kinds of resources in SENC models cannot be achieved by any other kind of material.

Information and communications technologies respect diversity because they have the capacity to adapt to the needs or requirements of each person, reducing differences in order to enable access to study programmes or the interpersonal communication of those who have greatest difficulties. As a consequence, schools that use technological tools in the classroom manage to reach all the students, independently of their special characteristics (Soto, 2013) .

For ASD students it is essential to draw them near to games that stimulate their senses. In particular, as regards children of the pre-school age, aged from three to six, we know that they acquire greater knowledge if they are stimulated with interactive exercises or games. To this is added the importance of the development of the senses in promoting the knowledge and attention of children with learning difficulties.

Of all the games that I have created for this children, what I have called 'Pantallita' is ideal for ASD children because by means of this game work is done on hearing, using videos and songs. Through the questions that are addressed to the pupil sound is obtained as an answer to a stimulus at the moment of choice when any of the twenty-four games that make up this software are used.

Visual support has a great deal of attention paid to it because the objects that have been chosen or created try to draw the pupil near to his or her reality, fostering in this way his or her recognition, and at the same time those who have most need as regards learning are helped. Computers and interactive digital blackboards can be used and they are very stimulating in developing the sense of touch, obtaining, indeed, immediate responses.

This is a game where various contents envisaged by curricular programmes of the cycle of child instruction are learnt and they belong to the three areas of learning. This is an ICT programme which has been produced in a special way for children in nursery schools but it can be useful at other stages of the educational pathway as well, above all with children who have special educational needs. The idea is that it will become an important stimulus in our pupils to stimulate their capacity for communication and visual-perceptive literacy, working on the basic vocabulary of the principal semantic fields that are addressed in nursery school.

In this game the pupil is allowed to work with the computer keyboard and with the mouse and in a constant way auditory information and verbal reinforcement are employed, with sound effects and natural and expressive voices that allow the pupil to understand the programme.

The role of images is fundamental because we very much base ourselves on them as complementary instruments to language in the transmission of knowledge during the processes of teaching and learning, as well as in communication. The messages have to be transmitted through images and we succeed in doing this with this game. Let us not forget that in the case of children with autism spectrum disorders a great deal of work is done with pictograms and images, both as regards school tasks and with respect to home ones, with a timetable, routine, meals and the presence of loved ones.

The objective is to identify these images with the auditory support. As a result, in this game this support is constantly found. In addition, the noises are produced by a four-year-old girl, thus making the pupil we are dealing with closer to this notion, given that it is a person who has the same age, and making the understanding of concepts more simple and fostering the learning process.

We can state that the availability of digital technologies in their various versions (desktops, portable computers, connection with Internet, WIFI, digital blackboards, tablets, etc.) in European schools, and Spanish schools in particular, is a tangible and evident reality and they are no longer seen as a problem or an obstacle in education (Área, 2009).

The use of the 'Pantallita' game and the use of interactive digital blackboards has improved the advance of the process of learning and teaching in our schools and has offered more opportunities to children who need greater attention.

Conclusions

We must be convinced that the use of technological tools is a great ally when we need to stimulate and motivate all children in the task of learning and teachers in their process of teaching and learning.

Teachers who use these resources are increasing in number and they offer them to pupils so that they interact with them in order to create and develop activities of all kinds, thereby supporting their process of maturity and autonomy and working on all the educational skills that are needed to ensure that the pupils are independent and able to look after themselves.

We must accept the challenge of reaching families and teachers of children with autism spectrum disorders in order to help them realise that the use of ICT can be of great help in the development of the teaching-learning process.

I am certain that teaching must provide space to a school that seeks integration, where we must all embody our role with responsibility in an active and serious way. Today teachers must have a clear idea that such a school has to be constructed with the help of information and communications technologies, fostering integration, so that differences between pupils are an enrichment and make us better in relation to society.

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1.4 Volunteers

MR. BOB AND
MRS. SUZANNE WRIGHT
Co-founders of Autism
Speaks Association,
USA

Remarks of Bob Wright

“Good afternoon.

Thank you – Your Excellency, Archbishop Zimowski, Monsignor Mupendawatu, Father Chendi, distinguished guests, colleagues and friends. It is an honor to be here at the 29th international conference of the pontifical council for health care workers. And, the first one on autism.

You have heard a great deal over the last day and a half about policies, strategies and ongoing studies. My name is Bob Wright and I am here to tell you that it is not enough.

My wife of 47-years, Suzanne, and I are the Co-Founders of Autism Speaks.

We will soon begin our tenth year working for our children, and I am proud to say we are the largest autism advocacy and science organization in the world. Both Suzanne and I will explain the work we do each day, but first I want to give you a little bit of history.

Our journey, you see, is a personal one. I was at the height of my career as a television executive back in 2001. We had travelled the world and met the most amazing people.

And then, in 2004, my first grandson, Christian, was diagnosed with autism.

There was little information and even less hope. The doctors gave my daughter Katie referrals for speech therapy and applied behavioral analysis and sent her home.

There were long waiting lists and few resources.

I will be honest.

We were lost. Afraid.

Our dreams for Christian, Katie and her husband Andreas vanished before our eyes.

But, we dug deep and I drew upon my faith and Marianist, Jesuit and Sisters of Charity education. Faith. Service. Community. Leadership.

And, discipleship to the Blessed Mother whose courageous faith helped her stand-by her son through all his suffering.

And so, with the investment of a close colleague, we began Autism Speaks.

And like, the Marianists, our goal at first was simply to raise awareness. To educate.

Back then in America, the prevalence of autism was 1 in 166.

It’s now 1 in 68 children. 1 in 42 boys.

We started visiting doctors and scientists. Taking trips to hospitals and universities.

Asking questions. And at first, getting very few answers.

Autism had turned our world upside down. And in growing numbers, there were many others like us.

Your Excellency, Archbishop Zimowski, you yourself have said, many of these families were “isolated.” “Marginalized.”

They needed the information we needed.

They needed support.

They needed community.

They needed hope.

And they needed leadership.

And so we planted the seeds of what we think has become the largest grassroots autism volunteer effort anywhere in the world.

It was simple. We walked for our loved ones with autism.

Together. In parks. On beaches. Through towns, cities and villages.

The walks helped anchor the family members and friends who simply did not know what to do for their loved ones.

And, we knew exactly how they felt.

At the walk, they could pitch in and hand out information.

They could entertain the children and the siblings of the children.

They could sell t-shirts, hats and pins.

They could organize their chaos and the chaos of others.

And as they organized – they supported each other.

They began to find community.

We have nearly 100-walks across America each year now with almost 500-thousand volunteers.

Most are the family members and friends of the three million American children, teens and adults who are affected.

But increasingly, there are others – good people who may not have a direct link to autism, but understand that it is the most pressing childhood developmental disorder before us today.

Each year, the number of volunteers we have multiplies. And, the money they raise goes back into the local community. As the Holy Father has said: “No one saves oneself. The community is essential.”

And so, it is incumbent on all of us to be volunteers. In fact, it is incumbent on all of us to press all doctors, hospitals, universities and legislators everywhere into action.

The needs of our autism families are great and largely – unmet.

Physical. Financial. Social. Spiritual.

At Autism Speaks we have raised and spent 500-million dollars, not just in awareness, but in scientific research, services to families, the development of treatments and passage of legislation.

Because our medical insurance in America is so vastly different than here in Europe, that has meant dealing with each state individually – and then lobbying the federal government to authorize more than three billion dollars in more research.

We have a full-time staff of 230 people and an army of volunteers.

But, we are one organization and we need every country and every government to recognize it’s their duty to help all people with autism.

And, there’s no time to waste. We hold the future of the world in our hands.

The financial, social and cultural ramifications of not doing enough for the rapidly rising number of people with autism is immeasurable.

And so, I propose to each of you to educate and advocate through governmental channels, in schools, and on social media.

Talk about early diagnosis and how we are sure it is critical for a good future.

And then, also consider another powerful route. As Christians, we can reach out to all the faithful through our local churches and dioceses. We can teach them to walk as Saint Francis, and indeed Jesus, did. Walk among the children, teens and adults with autism – not around them.

We can teach them to look our loved ones in the eye – instead of at them.

Hold them by the hand. We can teach them to listen. This is true volunteerism – from the heart.

And then, we can empower them with all we know about autism.

As I mentioned, over the last ten years at Autism Speaks, we have been working on the highest international and scientific levels. It’s time to bring our knowledge from the lab and the boardroom back to the community. So, as we are of service to them, those volunteers can in turn be of service to the 70-million families struggling with autism worldwide.

I am happy to say we have made incredible progress.

Many years of work with some wonderful partners in Bangladesh and Qatar, have led to the United Nations sanctioned World Autism Awareness Day. And most recently, this past May, the World Health Assembly adopted a formal resolution making autism a global health priority. That resolution is giving us the attention and the necessary urgency to develop critical tools for parents and care-givers.

The treatment gap is massive.

An estimated 85 percent of the global community with the biggest need is comprised of low resource countries. We are working with the World Health Organization and other NGOs to develop a curriculum for parents and caregivers. It will include teaching models on how to enhance communication, educate and deal with challenging behaviors, among many things. The goal, like the model for our walks, is to make it replicable anywhere. And, to make it available in every corner of the globe. For free.

The same is the case for our extensive investment in scientific research.

We have helped scientists study everything from environmental influences to biomarkers, and recently the role of the gastro-intestinal tract. And now, we are collaborating with Google to revolutionize genetic research into autism.

There is no other project like this in the world. It’s called “MSSNG.”

In a very short time period, Google will store and help us analyze the whole genomes of ten thousand people with autism and their families. And it will create a scientific portal – so that any scientist anywhere in the world can log on and study, investigate and share information. No more long plane rides. No more shipping of huge hard drives.

No more geographical, language or cultural boundaries. It will truly be a global lab.

As the Holy Father reminded us on the first feast of Saint John

Paul II, we as Christians are united in fellowship and faith. He said we must "be close to each other, share in the suffering of the least and the neediest and express our gratitude to everyone." Perhaps this is even truer of the autism community. We are all human. It is not easy to help.

And so, it is our job at Autism Speaks to create the walks and the curriculum for parents, to fund the research, to seek places for our loved ones to work and live as adults and build our army of volunteers.

Our work list is endless, but it is always grounded in a few goals: to give hope and strength, support and worldwide friendship. It is to bring this autism community together by reaching out our hands as Saint Francis did – one person and one family with autism at a time.

Autism must be the greatest grass-roots effort of our time.

It can be done. It has to be done. We have no choice.

The time is now.

Thank you very much for the honor of being here today.

Now here's my wife, Suzanne."

Remarks of Suzanne Wright

"Good afternoon everyone.

Thank you – Your Excellency, Archbishop Zimowski, Monsignor Mupendawatu, Father Chendi, distinguished guests, colleagues and friends.

I echo Bob's words.

It is truly the honor of my lifetime to be here at the Vatican and to have the struggles of our grandson Christian and the 70-million children like him, recognized by the Holy Father.

Let us all be honest. Autism is like nothing we have ever experienced before.

And there is a tremendous amount of suffering in our autism families.

It reminds me of the words of his holiness in his writing last year *The Joy of the Gospel*; "There are Christians whose lives seem like Lent without Easter."

Many parents and caregivers are tired. Confused. Sometimes angry.

We have been there. Their joy can be overshadowed by long days with children needing constant care. They may not know what to do to help. They may not know the word "autism" at all. And if, like my grandson Christian, their loved one has little language to help communicate, they may be a bit lost.

Autism is making us look at our world in a whole different way. Autism is a world where spoken language is not king. Where physical expressions of love like a hug can be difficult. Where social interaction may be even more problematic.

Autism is forcing parents and caregivers to slow down the frenetic pace of the modern world and look into the eyes of their loved ones – as Saint Francis did the leper.

It is opening their hearts and minds. And when that happens, the small miracles of autism take place. The miracle of understanding what's really important in this world.

The miracle of living in the moment. The miracle of learning to truly rejoice in the small moments. A new word uttered. A small task completed. The miracle of genuinely appreciating the beauty of our world.

In many ways, our children with autism are just like Saint Francis.

They may seem trapped in their bodies and yes, they can have physical pain, but yet they are free. Free from the constraints of time. Free from the burdens of money.

Free to experience and explore nature in all its glory. Free of cynicism. They are full of wonder. And in a very complex society, they have simple needs and desires.

As Bob explained, we began our journey at Autism Speaks by creating walks to get families involved and raise awareness. We now also have concerts and sporting events.

We sponsor all kinds of activities like swimming lessons and theatre performances.

We invest in science and job training. But, in our travels and at our annual conference with first ladies and dignitaries in New York upon the opening of the United Nations General Assembly for the last seven years, it became very apparent that there is a great disparity in the levels of awareness around the globe. And without awareness, there can be no education, understanding and compassion. And then, there can be no truly unified community.

In some places, the word "autism" is not even spoken.

It goes hand-in-hand with shame, disgrace, and harassment. Isolation. We are reminded of what the Apostle Matthew writes in the New Testament 25-40: "and the King will answer, 'In truth I tell you, in so far as you did this to one of the least of these brothers of mine, you did it to me." And so, we decided to lift up those places and indeed the world – with the universal symbol of hope, joy, love and, salvation.

And that is – light. And what travels faster than light? Only love.

For the last five years, we have spent every day asking anyone who would listen – to volunteer to light their monuments, businesses, places of worship and homes – blue – on April 2nd, United Nations sanctioned World Autism Awareness Day.

This year – all seven continents were glowing a beautiful blue as you will see in this video.

Pulitzer Prize winning author Edith Wharton once wrote: "There are two ways of spreading light: to be the candle or the mirror that reflects it." In the video you see many people being the candles – and some being the mirror too. And, they are all volunteers.

Parents, grandparents, aunts, uncles, cousins, relatives and friends who want to shake up the world in a gentle way. To inspire. To unify.

In the Holy Father's native Argentina, many parents and NGOs came together to light up La Casa Rosada, the office of the president – and to celebrate. This year the crowd was estimated at 10-thousand people. Here you see one of them giving Pope Francis a t-shirt. They are all volunteers.

In Brazil, Paula and Hermelindo de Oliveira and other autism parents took it upon themselves to get the Christ the Redeemer statue lit up blue as you saw in the video.

Volunteers.

In Japan, one autism mom managed to light up almost every prefecture!

In South Africa, it was the whole side of Table Mountain that honored our loved ones with autism. Again, the work of all volunteers. In Ghana, there was a walk and rally.

And in Kenya, one grandmother did what we did – and started an organization, the Autism Society of Kenya, to raise awareness. Educate. Advocate.

There are many, many stories. But they all go back to one thing – selfless love – and not turning our back to those on the margins. The Holy Father has said: "to change the world we must be good to those who cannot repay us." Our loved ones with autism won't be able to repay us in ways we are accustomed. Yet, their smiles and laughs have a way of being infectious in ways even more important. They open countless hearts and minds and in turn, draw in even more volunteers. And, that's what we need – because autism really does require the work of the village. People carrying the candles and some reflecting them. After today – you should be carrying a candle.

Our Senior Vice President for Scientific Affairs, Andy Shih and his team are working with the WHO on the curriculum Bob mentioned. They are also working with more than 60-countries as a part of our Global Public Health Initiative. They are using the body of knowledge we have amassed at Autism Speaks in almost a decade of constant work – and tailoring it to the needs of each country. We call them our *Autism Researchers without Borders*. They are eliminating the geographic boundaries – while still respecting cultural differences. And, what is most critical about this work is that it is also intended to get down to the level of the family and volunteer.

It is critical to use every tool possible to build on that foundation of selfless love, because most of the daily work has to be done at that foundational level – within the family and the small village of people taking care of the person with autism. It is the job of everyone here this afternoon to do this work and to seek other volunteers.

At the end of the extraordinary synod on the family, his Holiness Pope Francis reminded pastors to welcome and nourish all of the flock. And several times he has told the faithful to "not remain strangers to the pain of others." To "imitate Christ – and walk the streets of the world."

There is no time to waste. The rates of autism are rising rapidly.

So, let us all walk next to the 70-million children, teens and adults with autism around the world every day. Let us be a welcoming example for all other faiths.

Let us see with that pure vision of those with autism and past everything that has divided us. Let the most pressing childhood developmental disorder of this century be what finally brings every one of every faith together.

And, let us not forget that mere words will not help those families.

Volunteerism begins with us and begins in the heart.

So please, go home and carry a candle.

Light up every inch of your countries.

As Saint Francis did, we must take the hand of our grandson Christian and every other person with autism – and see them as beautiful pieces of the very rich, colorful puzzle of God's world.

We thank you again for this exceptional opportunity to be a part of this historic conference." ■

2. The Theological Foundations of Religious Education for People with Autism Spectrum Disorders

DON ANDRZEJ KICIŃSKI
*Full Professor of Theology,
Director of the Department
of the Theology of
Pastoral Care and Catechesis,
the John Paul II Catholic
University,
Lublin, Poland*

'I am seriously thinking about the fact of why an autistic person is called to life. It is really worthwhile thinking about this. I thought that there could be no meaning to this call for autistic people, the mentally defective and the mad. But I have had second thoughts. And this is not my opinion. Now I fight for an autistic life. I believe that it has a meaning. I alert all autistic people not to lose faith in their lives. Autistic people are as important as other people. I cry out: the autistic manage to love, to think, to believe in God, to be ashamed. They are sensitive people. They weep in loneliness' (from a text by Domenico, in his twenties, who has autism).

In Poland there are about 30,000 people 'touched' by autism, of whom 20,000 are adults and 10,000 children. The problem, however, has to be studied bearing in mind their family environment as well. Indeed, in Poland alone about 100,000 people are involved and the number of 'sick' people is growing constantly. Unfortunately, the causes of this phenomenon are not yet fully known. Therefore in this paper of mine I will not try to engage in an analysis of a quantitative kind but, rather, in one of a qualitative kind, that is to say I will try to find an answer to the appeal of every person who is 'touched' by autism or their parents and who look for a 'why' to their suffering and their pain.

The advance of medical and pedagogic research has demonstrated that people 'touched' by autism have to face up to a vast gamut of difficulties. Autism is a disturbance of development that is extremely complex and conditioned biologically and where three fundamental areas of qualitative irregularities have been identified: in social interaction; in the ability to communicate; and in reduced, repetitive and stereotypical models of behaviour, interests and activity. For example, an autistic child when he or she is together with other children does not look into their eyes as we would expect. However, even though one does not know 'how', they nonetheless look at us, albeit in their own way. At this point a spontaneous question arises: how does the Catholic Church respond to the mystery of the lives of people 'touched' by autism? What does it do to ensure that Domenico does not weep in loneliness and that his appeal is heard?

St. John Paul II and Benedict XVI: the Builders of Bridges between the Normally Endowed and the Disabled

To employ an image, one could say that catechesis with people who are 'touched' by autism is in symbolic terms a 'meeting on a bridge'. In order to reach the world of people with autism one has to build bridges and enter 'their world' so as to then invite them to enter 'our world' which for them is often incomprehensible. There are already a significant number of us (but perhaps still too few in number) who are beginning to build real bridges that reach this world.

The term *pontificus maximus*, which comes from Roman antiquity, when translated literally means 'the greatest builder of bridges'. In the case of Popes, it defines the mission of the successors of St. Peter. St. John Paul II, indeed, while he was building a large number of bridges between cultures and religions, also built bridges between people with various kinds of disability and the 'world'. In his catechesis he did not neglect the most difficult problems. He was the first Pope to ask himself, and to pose to others, the following theological question: are people with mental disorders created in the image and likeness of God? In his address that he gave during the international conference that was organised by the Pontifical Council for Health Care Workers in 1996 in Rome, when pointing out that man is created in the image and likeness of God John Paul II emphasised that philosophical and theological thought perceived in the mental faculties of man, that it is say in his reason and his will, the most evident sign of his likeness to God. These faculties make man a persona capable of knowing the Lord and establishing a dialogue with Him. These are the privileges that make a human being a person. Through this statement, the Pope proposed anew the Christian value given to man as a creature of God and at the same time expressed the teaching of St. Thomas Aquinas about the human creature understood as a person: 'Person signifies what is most perfect in all nature, that is, a subsistent individual of a rational nature'.[1] The Holy Father made clear that 'the whole man, not just his spiritual soul, including his intelligence and free will, but also his body shares in the dignity of "the image of God."' He twice quoted the words of the teaching of the *Catechism of the Catholic Church* where this work states that the body of man 'is a human body precisely because it is animated by a spiritual soul, and it is the whole human person that is intended to become, in the body of Christ, a temple of the Spirit' (*Catechism of the Catholic Church*, n. 364). St. Paul wrote: 'your bodies are members of Christ? ... You are not your own.... So glorify God in your body"' (1 Cor 6:15,19-20). Hence the need to respect one's own body, and also the body of every other person, especially when it is touched by suffering (cf. *Catechism of the Catholic Church*, n. 1004).[2]

St. John Paul II emphasised that every person is an end in himself or herself and thus cannot in any case be used as a means to achieve certain ends, not even in the name of the prosperity and the progress of the whole community. God, in creating man in His own image, wanted to make him a participant in His lordship and His glory. In entrusting to him the mission of taking care of the whole creation, He thought of his creative intelligence and responsible freedom. The Pope in his address, when evoking the Second Vatican Council which explored the mystery of man by opening up new horizons, declared that there is 'a certain parallel between the union existing among the divine persons and the union of the sons of God in truth and love' (*GS*, n. 24). The important truth for everyone, and especially for people with intellectual disabilities or autism, lies in the fact that when God turns His gaze to man the first thing that He sees and loves in him are not the works he manages to achieve but the image of Himself. It is specifically this image that confers on man, 'appointed by God' the lord of all creatures (cf. *LG,* n. 12), the capacity to know and to love his Creator. In conformity with this, the Church recognises that all men have the same dignity and the same fundamental value, independently of autism, Asperger's syndrome or intellectual disability.

Every person, independently of his or her various levels of mental disorder, is created in the image and likeness of God. One may say that from an ontological point of view faith and reason unanimously recognise the full human dignity of people with different mental dysfunctions. On this point, however, St. John Paul II exhorted us to set in motion prospects of change in the deontological field. He directed our attention to the problem of indifference towards these people and forms of behaviour which compromise their dignity and observed that the suffering connected with mental disorders, which are seen as absurd and incomprehensible, assimilate these people to Christ and make them participants in his redemptive passion. The current teaching of the Church encourages Christians to demonstrate through concrete forms of behaviour that no mental disturbance involves an impenetrable abyss which can impede the establishment of relationships of true love with those people who suffer from it. This is the case not only when the mental faculties of a person can be said to be very limited but also when they seem completely absent. We find again here the encouragement of a shared commitment for the benefit of these people and the correct use of human, scientific and economic-social resources, the outcome of cooperation between science and faith, between medical doctors and educators in faith.

The Second Vatican Council had a notable influence on the development of dialogue between faith and culture. For this reason, the teaching of the Church on disabled people, which is anchored in the spirit of the Gospel, criticises the approach of the contemporary world which is bewitched by the successes of science and technology and is in a state of confusion because of ideologies and ethics that are extraneous to the Gospel. This, however, does not discourage the Church which constantly looks for new forms of dialogue which can allow the genuine message of the Gospel to penetrate the minds and hearts of the men of our epoch.

Two principal aspects of this problem exist which are intertwined and correspond to the two dimensions in which the Church works. The first aspect relates to the evangelisation of cultures; the second, on the other hand, concerns the defence of every man and his right to development, independently of any limitation that may exist.

The Church is aware that she has before her a long and important process of inculturation so that the Gospel can reach the essence of culture. The inculturation of faith is a task of the whole of the ecclesial community. It concerns all the activities of the Church and not only those connected with theology (or catechesis) which would not be able on their own to meet this challenge and yet, however, theology (catechesis) conserves a great responsibility for the inculturation of faith because it is called to open up specific areas of implementation. To proclaim the gospel to Christians 'touched' by autism, to every man who lives in a specific culture, means, in fact, to really experience the search for pathways of salvation for everyone, with the exclusion of no one.[3]

Pontifex maximus – the building of bridges – is the mission of the successors of St. Peter. After St. John Paul II, Benedict XVI also demonstrated all of his great commitment on behalf of disabled people. For example, the doubts of those who did not know whether Holy Communion could be received by people with deep intellectual disabilities or by those people unable to communicate orally, as is the case with some people with autism, were clarified. Benedict XVI in his post-synodal apostolic exhortation *Sacramentum caritatis*, when expressing his concern to assure sacramental communion to all people with mental disorders, emphasised that these people receive the Eucharist in faith, in the faith of their families and of the communities that accompany them as well (cf. *Sacramentum caritatis*, n. 58). Benedict XVI helped parish priests and catechists to build a 'bridge'[4] in all peace of mind by eliminating in a final way the distinction between disabled people who are fit to receive the sacrament of Christian initiation and those who are not. Indeed, the condition thanks to which one can cross the 'bridge' of the sacramental encounter with Christ is no longer the mystery of autism or the level of mental disability, and not even the lack of oral communication, but the faith of the family or the community which accompanies these disabled people.

The Theology (and the Catechesis) of People with Autism

The theology of people with autism is based above all else on the Bible. It teaches that man is created 'in the image of God' (Gen 1:27) and as the Second Vatican

Council observed he is capable of knowing and loving his Creator (cf. *LG*, n. 12). On this point the etymology of the word 'catechesis', which comes from the ancient Greek *katecheo* (which means literally 'to sound out' 'to make sound out', 'to re-echo'), can help us in our reflections. Catechesis for people with autism is certainly a difficult challenge but it refers in fact to the echo of the Word of God which says: 'And God looked at everything he had made, and he was very pleased' (Gen 1.31).[5]

In the past some members of the Church, most of the time, expressed the opinion that the words of those who described the suffering of disabled people were not exhaustive because they were convinced that another dimension existed which could not be reached by the senses or by human reason. However, one can say, respecting the genuine Christian value of life, that this dimension, described as 'suffering' by every disabled person, rises to a deeper meaning which transforms weakness into strength and poverty into riches. The teaching of the Church, which is based upon the mystery of the Cross of Christ, is faithful to the Word of God, where it is stated that 'God chose what is weak in the world to shame the strong…so that no human being might boast in the presence of God' (1 Cor 1:27-29). This originality of Christianity is expressed in the fact that whereas people with autism are seen as weak and sick by other people, before God, instead, they are great because of what they are. Even though arduous, for believers this is a truth that should be accepted because in the Kingdom of God it is not the powerful, the eminent, and those who want to occupy the first places who are the notables: the least, the weak, the poor and those who suffer are the ones who occupy such places.

The teaching of the Church since the Second Vatican Council has strongly emphasised the truth that man is ennobled by God who has called him to life, has accepted him and leads him to perfection. The 'yes' of God the Father bends down over the healthy and the sick, the industrious and the not industrious, and people 'touched' by autism and deep intellectual disabilities, ensuring that every day of human life is an achievement in the fulfilment of life as a gift which is worthy of being lived. This teaching is especially addressed to those fathers and mothers who, with full dedication and often not understood in their own contexts, take care of and love their children who are sick and at times are disabled for the whole of their lives.[6]

Most of the time it is the case that neither parents nor children, nor the surrounding social context, realise the great effort that the new situation, which hitherto has not been experienced, will require. It is known that parents who are expecting the birth of child want it to be healthy, to be successful and to develop and grow up like other healthy children. Every diagnosis that reveals that the new born child is in a bad state of health is a terrible blow for the parents, a mental shock, because many parents, for example in relation to autism, given that they have never heard it spoken about before, when they learn about it because of the diagnosis, before or after birth, feel that they are not equipped for this situation and unable to address the problem. It is specifically at this moment that the Christian community must accept the challenge and surround the parents of children with autism with attention at a time that is so dramatic for the parents. It is certainly the case that it will be very difficult to find answers to the questions that they pose after they have found themselves in such an unexpected situation but it is the task of the Christian community not to offer responses to every event but, rather, to try together, in a spirit of faith and reason, also to help the parents of children with autism to overcome stereotypical thinking about the causes of such a state of health.

In the teaching of the Church since the Second Vatican Council we should note first and foremost the attention that is paid to various forms of disability and then, as regards autism, and this despite the advances of medical science, it should be observed that the opportunity is taken to stress that man is anyway a mystery but finds in Christ his true light (cf. *GS*, n. 22). This disability is defined above all else as a great trial which at the same time is a mystery. For believers, the life and the work of Jesus Christ as he passed down the roads of Palestine is essential. He very willingly drew near to the sick and suffering with his infinite human-divine compassion, at times bringing the gift of healing as well. The Magisterium of the Church invites us to turn today to Christ to receive the light that will illumine the mystery of suffering and also to receive the grace to be able to accept it with humility. Christ does not ask us to shut our eyes in the face of suffering. The Magisterium emphasises that Christ pushes our gaze to a deep level so that we may believe that in the body of a suffering person not only is human life present, with all of its dignity and all of its rights, but also the true life of God that springs from baptism.

The concern of the Church to provide a correct catechesis to people with autism is also expressed in the correction of mistaken opinions. The idea about life with limitations which is held by people who are normally endowed rarely corresponds to reality and is rarely an expression of an understanding of people with autism. Their imperfections are far too often identified with suffering, pain and unhappiness, that is to say with negative elements.[7] Theological thought since the Second Vatican Council has paid attention to the fact that the positive aspects and beauty, which are present in the lives of people with autism, are not sufficiently valued and appreciated. It is certain that these people for many reasons live their condition as a great limitation. This situation generates in them the perception of an unjust treatment in daily life and therefore personal injury. They rarely take part in public life, even though they have the same rights as other people, because the noise, the smells, the urban chaos, and types of food other than the ones they prefer and so forth, for example, become for them authentic barriers. Despite this, they do not see themselves as people of an inferior value to others. On the contrary: many of them see themselves as ‘different’ people, that is to say that they have other ways of expressing themselves as individuals compared to other people. Indeed, they discover that their talents and their abilities are an opportunity to build their own daily lives, asking, in their turn, to be respected as regards the way they are seen in the world. Only when this is accepted, will so-termed normally endowed people know the special character of the lives of people with autism and confer value on them

Conclusion

The methodology of the catechesis of the Catholic Church for people ‘touched’ by autism involves above all else becoming their ‘travelling companions’, fostering their full entrance into the way of Christian life.[8] Naturally enough, the fundamental principle of reference is that of a dual faithfulness: to God and to man; the educator in faith can bear in mind important aspects that derive from psychology and special pedagogy, remembering, however, that this does not exonerate him or her from the duty of bearing in mind the centrality of divine Revelation and above all else the way in which God has revealed Himself, what in other terms is described as the ‘pedagogy of God’. What has been said, as a fundamental aspect, opens up to the need during catechesis to interact with the therapists, for example schools and the parish communities, and above all else with the family. To sum up: to create what is called an ‘integrated catechesis’, that is say a catechesis that involves a network of relationships, where, for example, the school, special institutes, foundations, associations and the Church itself are not juxtaposed realities or, worse, isolated from each other, but realities that are connected with each other, thereby reflecting, as far as concerns us, that Christian value of constructive dialogue animated by love of one’s neighbour which is a fundamental characteristic of the disciples of Christ. God is not an abstraction – He is the Living God. He installs a relationship with His creature, whose capacity for reasoning is known by the Creator. We would say that is it ‘relative’ to the creature.[9]

A person with autism cannot be seen as ‘strange’ or ‘without’ contact with reality. Indeed, one should change the type of approach, valuing his or her capacities, aware that this is a gospel service for everyone so that nobody, with no individual excluded, loses their talents but increases them, certain that the person ‘touched’ by autism, as well, has received them from God (Mt 25:14-30). ■

Notes

[1] John Paul II, ‘Address to those taking part in the eleventh international conference organised by the Pontifical Council for Pastoral Assistance to Health Care Workers’, 30.11.1996, in *L’Osservatore Romano* (Polish edition), 18(1997) n. 2, pp. 47-48.

[2] *Ibidem.*

[3] Cf. A. Kiciński, Ewangelizacja środowisk życia osób niepełnosprawnych, (‘Evangelisation in the Life Environments of the Disabled’), in P. Mąkosa (ed.), Katecheza ewangelizacyjna. Poszukiwania koncepcji, (‘Cathechesis and Evangelisation. The Search for a New Approach’) (Lublin, 2010), pp. 219-226.

[4] Cf. Ufficio Catechistico Nazionale, *L’iniziazione cristiana alle persone disabili* (Bologna, 2004), p. 63. The key to this publication lies in the answer to the question: ‘why be parsimonious in giving gifts of the grace of God when the Lord is always abundant?’

[5] Cf. A. Kiciński, Katecheza osób z niepełnosprawnością intelektualną w Polsce po Soborze Watykańskim II, (‘Catchesis of the mentally disabled in Poland after the Second Vatican Council’) (KUL, Lublin, 2011), p. 22.

[6] The development of teaching after the Second Vatican Council on the role of disabled people in the life and the mission of the Church is to be observed in various documents of the local Churches: Uchwały I Synodu Dicecezji Katowickiej, Wiara, modlitwa i życie w Kościele Katowickim (Katowice-Rzym, 1976); Conferenza Episcopale dell’Emilia Romagna, L’accoglienza degli handicappati (Leumann (TO), 1981); United States Conference of Catholic Bishops, Resolution on the Pastoral Statement on Persons with Disabilities (Washington, 1988); United States Conference of Catholic Bishops, Pastoral Statement of U.S. Catholic Bishops on Persons with Disabilities (Washington, 1989); IV Synod Dicezji Tarnowskiej (1982-1986), Ad imaginem ecclesiae universalis (Tarnów, 1990); Équipe de Catechistes du Diocese de Dijon, Merveilles en chemin. Un parcours catéchétique pour des enfants et des jeunes marqués par une déficience intellectuelle ou mental (Centurion-Privat, 1991); Sekretariat der Deutschen Bischofskonferenz, Zum Religionsunterricht an Sonderschulen (Bonn, 1992); Ufficio Catechistico Nazionale, La catechesi dei disabili nella comunità (Bologna, 1993); Secretariato Nacional de Catequesis, Annunciar a los pobres la Buena Noticia. Magisterio de la Iglesia y minusvalías (Madrid, 1995); Ufficio Catechistico Nazionale, La catechesi dei disabili. Documenti – Studi – Esperienze (Rome, 1995); Ufficio Catechistico Nazionale, Non voglio risorgere senza di te. Linee di educazione cristiana dei disabili (Bologna, 1996); Bishops Conference of England and Wales, Valuing difference. People with disabilities in the life and mission of the Church, 3.01.1998; [on-line] http://www.catholic-ew.org.uk/resource/vald01/ (01.05.2007); A. Comploj, M. Ettel, R. Köhler, G. Neuhofer, A. Petz, M. Appesbacher, ‘Lehrplan für den Katholischen Religionsunterricht an der Sonderschule für schwerstbehinderte Kinder’, in Bundesgesetzblatt für die Republik Österreich n. 346 del 29.09.1998, pp. 2163-2189; Deutsche Bischofskonferenz, Grundlagenplan für den katholischen Religionsunterricht an Schulen für Geistigbehinderte (Munich,1999); II Polski Synod Plenarny (1991-1999) (Poznan-Warsaw, 2001); Konferencja Episkopatu Polski, Dyrektorium katechetyczne Kościoła katolickiego w Polsce (Krakow 2001); Ufficio Nazionale per la Pastorale della Sanità, Talità kum. Il disabile e la Chiesa accogliente (Bologna, 2001); United States Conference of Catholic Bishops, Guidelines for the Celebration of the Sacraments Persons with Disabilities (Washington, 2002^4); Caritas Italiana, Un dolore disabitato. Sofferenza mentale e comunità cristiana (Bologna, 20039; Conference des Éveques de France, Assemblée plénière 2002. Textes et documents. La catéchèse, le marriage, des temps nouveaux pour l’Évangile, la place de l’Église dans la société française, l’Europe (Paris, 2003); Die Deutschen Bischöfe, ‘UnBehindert Leben und Glauben teilen. Wort der deutschen Bischöfe zur Situation der Menchen mit Behinderungen’, 12.03.2003, in Die deutschen Bischöfe (2003)70; National Catholic Partnership on Disability, Opening Doors of Welcome and Justice to Parishioners with Disabilities. A Parish Resource Guide (Washington, 2004^2); Ufficio Catechistico Nazionale, L’iniziazione cristiana alle persone disabili. Orientamenti e proposte (Bologna, 2004); Konferencja Episkopatu Polski, Podstawa programowa katechezy Kościoła katolickiego w Polsce (Krakow, 2010), pp. 103-126; Komisja Wychowania Katolickiego Konferencji Episkopatu Polski, Program nauczania religii rzymsko-katolickiej w przedszkolach i szkołach (Krakow, 2010), pp. 225-233.

[7] Cf. Die Deutschen Bischöfe, ‚UnBehindert Leben und Glauben teilen. Wort der deutschen Bischöfe zur Situation der Menchen mit Behinderungen’, 12.03.2003, in *Die deutschen Bischöfe* (2003)70 s. 10-12.

[8] Even though the community is irreplaceable, in the case of catechesis with people ‘touched’ by autism’, in practice individual planning is required. Cf. A. Kiciński, ‘ndywidualny Program Katechetyczny (IPK) dla osób z niepełnosprawnością intelektualną i autyzmem. Studium przypadku’ (‘Individual planning of catechesis for people with intellectual disbilities and autism’), Katecheta, LV (2011)1, pp. 4-11.

[9] Cf. H. Bissionier, ‘Come affrontare gli ostacoli e valorizzare le attitudini nell’approccio catechetico con persone handicappate mentali’, in Ufficio Catechistico Nazionale, *La catechesi dei disabili nella comunità* (Bologna, 1993), pp. 19-20. As 70% of people ‘touched’ by autism also suffer from mental disorders, the recommendations of H. Bissonier about the approaches to be adopted in the preparation of the sacraments could be useful: ‘The first approach is to catechise these people without bringing them to receive the sacraments on the pretext that they are not capable of doing so…A second approach that seems to me to be profoundly mistaken lies in giving the sacraments, and in particular the Eucharist, without any preparation…The third approach to be avoided is that of making access to the sacraments the only purpose of the catechesis’ (pp. 22-23).

3. The Pastoral Accompanying of Families whose Members have Autism Spectrum Disorders

MSGR. PIERANGELO SEQUERI
Member of the International Theological Commission, Italy

I would like first of all to express my thanks for this invitation, also expressing my appreciation of, and gratitude for, the organisation of this meeting which is so broad and detailed and which is on a subject that touches many families so deeply and awaits greater sensitivity on the part of the community and government institutions.

Following in the furrow of this sensitivity, believers themselves must never stop extending and updating their best experiences of accompanying and support, in which, indeed, many individuals and many associations are already generously involved on behalf of the Christian community and as witnesses to evangelical nearness. Events such as this, in which many and qualified forms of expertise are taking part, together with testimonies of work in the field, bring with them instruction and encouragement which must be sown, so to speak, in all local contexts. To the furrow of this experience, albeit within the limits of my knowledge and expertise, my paper also wants to belong. There is a dual background to these reflections of mine. On the one hand, they derive from my presence for almost fifty years in family worlds that carry in their wombs these children who are so wounded and so special. I was one of the people who contributed at the outset to the 'Faith and Light' experience of my city, a movement of a Christian outlook which is especially dedicated to accompanying family units that are sorely tested by the psychic and mental frailty of their children. The inspiration for this movement is the extraordinary charism of Jean Vanier (and Hélène Mathieu) who, in addition to creating a community of ongoing living together, stimulated the birth of a larger network of reciprocity and sharing of these families with other families who live in the same local contexts. Sharing is fostered and animated by a nucleus of families who share Christian faith and membership of the Christian community. However, this movement is totally accessible and hospitable to broader participation which is defined by the goal of mutual help and escape from isolation. I believe that it is a great good fortune – indeed a grace – to have had an encounter with this experience at the beginning of my priestly ministry in a parish in Milan. The central element of this kind of accompanying is a commitment to fostering relationships involving friendship and trust between families, beyond specific individual services and beyond concentration on the limitations and the treatment of wounded children. All families, in one way or another, have a life history in which the problems of adolescence, daily vicissitudes, and wounds and losses relating to their children, bring elements of destabilisation and experiences of authentic powerlessness. The encounter of friendships and the exchange of trust are a source for a *redemption from isolation* of both parties.

Families put to the test by a permanent wound are thus in a meaningful way freed from their special extraneousness and reacquire parts of normality in dialogue with other patients about their life problems and with their children. In this, they also adopt an active role in communicating their experiences and providing support. The other children are notably lightened of the special difficulty that accompanies their maturation in a family context which is inevitably concentrated (and at times even forcibly 'requisitioned') on the problem of a brother or sister who is in a state of difficulty. They meet other children and other families where they experience an absence of prejudices, commonplaces and badly controlled embarrassment. They are certain that their family situation will not be obsessively 'justified' and that it will not make them 'invisible', if not, that is to say, an accessory element of a handicap that absorbs attention completely. The other parents and children, in their turn, will experience a different experience that is important for the *normality of real life*. Indeed, it teaches them to address the unforeseen in family and social life where affections, ties and the most normal attitudes are put to the test. At the same time, however, they will experience the establishment of nearness and mutual attention within the framework of the habits of family life in all spheres: playing, studying, working, going on trips, organising times and commitments, eating a pizza, and so forth. Common prayer, convivial meetings, or a weekly outing mark in a very simple way the symbol-points around which the trust-imbued and differentiated network of relationships is developed. These are normal relationships which integrate the exception by orchestrating it together with the happiness and adversity of life, whose joys and pain are experienced together.

The effect, therefore, of the positive idea of putting together in relationships family units, rather than developing simple care for individuals with individuals, is *polyvalent* and generates transformations of arrangements which affect the level of real life of *all* the components of the family and all the *parts* of existence. This also produces an excellent development of the function of being a personal, family and communal filter which helps to modulate and harmonise the times and forms of life with necessary forms of therapeutic care. In this way, support and accompanying, rather than polarising around the clinical outlook and the therapeutic action, makes them sustainable and at the same time works against their possible effect of being exaggerated treatment or an impounding within the mental and relational cage of the handicap.

A human person lives emotions, desires, interests, potentialities and stages of his or her life that are beyond the limits of the interpretation and computation that are assigned to them within the nosographic picture, to which at times *everything* is led back and from which *everything* is deduced. During the early years of my experience in this field, a long time ago, I was also involved in a critical way in this hidden reductionism. This is a reductionism which although it continues to proclaim the individuality of the individual and respect for the person, in practice thinks that beyond a certain threshold of psychic and mental deficit we are legitimated in seeing the handicap as a global interpreter of all human and personal qualities, including those which in other children, on the other hand, we try to see in relation to the fact that they are children or adolescents, or adults, or simply human beings that are developing who have life histories (and not only involving illness) that form their set of experiences and possibilities or impossibilities. I usually summarise this idea, which I have also developed in the field of my professional research as a philosopher and theologian, with the following slogan: 'a child, however grave or disabling his wound may be, remains human'. In the case of handicap of a psycho-mental kind (or *disability* as people would have it today adopting a point of view that is borrowed from competitive society which is then corrected clumsily and nominalistically into *diversely abled*), sliding into this hidden schema of interpretation is especially easy and, without an adequate training, it is practically ineluctable.

From this point of view, after a few years of this happy experience I was internally stimulated to look for a more concrete way by which to contribute to a visualisation of this different approach in the way of thinking about and creating opportunities. In the field of my work as a researcher I tried to expand, during a period when I taught support teachers, the space of an understanding of the human that would be able to incorporate (without unsuitable mystic or sentimental emphases) the anthropological subject of wounds, limits, and permanent diversity which within the human are necessarily shared. It is therefore the *how* that makes the difference. This is because the *potential* that can be evoked by the shared human, which increases in proportion to the ties that it attracts and activates, is always greater and deeper than any *deficit*. And I imagined that I could have also invested my musical training (which at one time was an inheritance and vocation that was almost a matter of obligation but which was later suspended because of another call, which, however, in the end, I discovered from a completely different perspective) In this way the Hexagram Centre was put together and developed with different stages of experimentation. Its essential picture – do not jump in your seats – is the following: great music activates refined syntactic structures (connected with intelligence, relationships, symbolisation and self-consciousness) where their development through oral communication and/or direct communication is practically inhibited as well. The idea that forms the basis of this research, and of the method of the pathway of rehabilitation and transformation that derives from it, is a conception of the musical-human as an experience of the performance-affections of logical thought of high complexity (and not only as an instrument of expressive games or as a gratification of the emotions or of the libido) which has still not been very much assimilated in the field of the notion of formation (whether musical or general formation). I will not dwell on the dynamics of this experience, to which one can easily gain access through Internet. I will confine myself to pointing out that in the subjects (and family units) where it has been demonstrated that it offers results as regards transformation which are especially interesting, there are first of all children and boys and girls affected by autism spectrum disorders (in the broadest sense which includes manifestations connected with the constellation of mental disorders of various kinds or environmental contexts involving especial deprivation). As regards the direction to the elaboration of anthropological and clinical bases, and also a detailed description of the work method and the connected specialist training, I refer the reader above all to the publications of Dr. Licia Sbattella of the Hexagram Centre and a member of the G3ict Steering Committee (United Nations) for special and technological education (cf. L. Sbattella, *Ti penso, dunque suono. Costrutti cognitivi e relazionali del comportamento musicale*, Vita e Pensiero, Milan, 2013).

The focus that should be emphasised in particular at the present time from the general point of the civil community, but in a completely special way through the witness and practice of the Christian community, seems to me to have been well identified. Psychic and mental handicap, and in a special way the demanding and delicate reality of the syndrome of autism, in recent decades has only with difficulty been subjected to attention and recognition which, indeed, before the middle of the last century were practically inexistent.

The affection, courage and tenacity of parents, first of all, but also a new sensitivity on the part of clinical psychology and civil society, by now have opened up horizons of care, practice and care which deserve to be appreciated.

They should certainly be pursued and improved. There is still a great deal of road ahead of us, naturally enough, many frontiers remain to be explored, and perhaps some confusions as regards approaches which are more or less clinical or more or less involve the perception of miracles should be removed in a resolute way. In this context, nonetheless, the new frontier seems to be specifically that which the organisation of this international conference has also rightly highlighted. *The new frontier is that of an overall and mentally equipped attention paid to the kindred and family unit*, which has hitherto been largely neglected (or superficially called into doubt, which is even worse). The Christian community, adopting in the right evangelical way the whole of this dimension, and without superficial simplifications or elusions from the good practices made available by the advance of serious clinical science and suitably sensitised social attention, can, and must, honour in the best way possible the appeal that is made to it by the Word of God as regards the smallest, the most vulnerable, and the most distanced or forgotten about. This is a yardstick as regards the quality of faith of the whole community (as it already is for the whole of civil society). This is a matter of balancing the care given to special and wounded children who are behind invisible and inaccessible barriers acting against our normal capacity for relationships, on the one hand, with a rehabilitation of the shared human of their parents and their brothers and sisters, on the other. The courage of their dedication deserves this. The authenticity of our appeal to the sacredness of life and the dignity of the human imposes this. They must be restored to a history of social life that is shared in love and also withdrawn from a history of family life that has adapted to isolation.

The family (parental, relational) framework is not only a fundamental context for the first self-identification. It is also a basic model for every further educational relationship in order to achieve a good life of relationships. No exceptions can be given because of a handicap; not even a handicap involving autism. In his or her development as an adolescent, a child, however, needs to reduce that system of relationships so as to be able to develop a necessary openness to the more complex social and human world of life.

Ecclesial hospitality, which should be generous and not invasive, must demonstrate great intelligence and delicacy when faced with the (not rare) need to work through the easily distorted influence of *certain commonplaces about acceptance of the design of God* which may appear devout but which, in reality, owe themselves to a very ancient ambiguity about the sacred which is not purified by the gospel of Jesus Christ (cf. P. Sequeri, *Il timore di Dio*, Vita e Pensiero, Milan, 2010³). Authentic faith in God involves the trust that He will support all efforts – every good invention of therapy, every creative resource of solidarity – in order to redeem, as well, the wounds and the gravest limitations of a worthy life. 'In truth I tell you, whenever you did it to one of these smallest brethren of mine, you did it to me' (Mt 25:40). This is not a special supplement to normal religious and Christian duties that are entrusted to a special generosity of the heart. It is, rather, an absolute and not optional discriminant of the judgement of God about the real quality of faith. And this applies to *everyone*. It is *necessary* and thus *normal*. The principle of the subsidiarity of charisms within the Church, on the other hand, is very creative and very vital in inventing ways by which people carry each other's burdens, distributing them to each member according to his or her capabilities. Stimulating the network of skills to make it sensitive for the human that is lived, and not only for the defective organ, and encouraging good involvement and discouraging forms of sterile parish or school competition, today can express a disinterestedness and an affection that are equally necessary in order to reanimate the alliance of knowledge and belief, and of technology and affection. By now in our society it is the *human as such* that is tested in its capacity to remain faithful to the dignity of human life: in science and thought, in narration and communication, in work and in professional life, in education and treatment (cf. P. Sequeri, *L'umano alla prova. Soggetto, identità, limite*, Vita e Pensiero, Milan, 2002²).

The cocoon of the 'autistic spectrum' certainly challenges – and often to the limits of our capacities – our general ability to achieve the reciprocity of man for man where communication appears specifically as a challenge to the 'commonplaces' of intimacy and relationships. And yet this is specifically the setting where the love of God must be communicated: if treasure can be obtained from unexpected ties of love specifically here, then this can take place everywhere. And this applies to everyone. A believer, for his or her part, well knows that the theological heights to which the Lord took and also sealed fraternal love for neighbour is the pearl of Christianity. It is the treasure that makes Christianity recognisable by everyone. The Christian community which bears witness to, and worships, God in the name of Jesus cannot leave the place of its most vulnerable children and their fathers empty. Only if we are reconciled with them, as regards abandonment, can we serenely take our offering to the altar. Together with them. ■

4. EXPERIENCES FROM SOME CHRISTIAN COMMUNITIES

4.1 Experiences from an African Community: A Case of Northern Malawi

DR. CHARLES MASULANI-MWALE
Director of Services,
St. John of God
Hospitaller Service,
Mzuzu, Malawi

Some indicative statistics about Malawi:

Malawi has a total Population of about 15.2 million people. She has an under-five mortality ratio of 110 per 1000 live births and a crude death rate of 12%. Currently life expectancy at birth is 54 years. While under-five underweight stands at: 21%, the national HIV/AIDS prevalence is at 11% with more than 650,000 children 18 orphaned by HIV. On service delivery we have a Doctor/Population ratio of 1:55,000 and a Nurse per Population of 1:4,100. There are only 4 Central Hospitals, 25 District Hospitals and 2 *Mental Hospitals,* including St. John of God.

On disability, about 190,000 people have with disabilities in Malawi (2.9% of the population of the population of which, 54% is male and 46% female. Persons with disabilities face numerous challenges leading to their exclusion society, making it difficult for them to access their fundamental social, political and economic rights. 90% of these live in rural areas with little or no access to rehabilitation services. They are mostly impoverished, abandoned, uneducated, malnourished, discriminated against, neglected and vulnerable. Our recent study shows 19% prevalence with huge burden of care among mothers who are the main carers.

Our experiences with Autism

It is very difficult to diagnose autism and few children presenting with autism are correctly diagnosed. Not much research is done and there is need to promote evidence based practice in this area.

In spite of having good written policies and the whole Ministry responsible for disabilities there are very few services for disabilities apart from those offered by missionaries and a few NGOs.

With this back drop, most parents present with huge burden of care, they normally require support and the well off seek services in South Africa.

To respond to this in November 2004, a **n**eeds assessment was done for children with disability and as a result, the St John of God Brothers opened the Child Development Centre as a home for the Children's Programmes. Later, Elvira Institute of Special Education was opened to provide four classes for children with disability. In July 2009, having completed the required modules of training for staff and community volunteers, the Child Development Centre was certified by Portage International as the National Training Centre for Malawi.

The center aims to promote early interventions services; teaching, learning for children (0-6years) and nutrition supplementation; pre-vocational interventions; postural management and equipment production; recreational activities and counselling and skills building for parents.

Portage program provides early services for 0-6 year old children with disabilities in homes with volunteers in partnership with maternity units

The Special Needs Education School offers a range of supports for disabled children.

Other programs for children with all other disabilities include: Postural Management Clinics; sensory Motor Clinics; Community Based disability clinics; feeding programs for those children with co-occurring disability and malnutrition and Mother Support to promote sustainability through Self Help Groups for women.

For more information visit: www.sjog.mw

Thank you. ■

4.2 Animating Hope in Christian Communities throughout America

DR. JANICE L. BENTON
Executive Director
National Catholic Partnership on Disability,
Washington, DC, USA

Your Holiness, Your Eminencies, Excellencies, Clergy, Religious, and Brothers and Sisters in Christ,

It is a great honor to be with you for this important international gathering at which we are considering the needs and gifts of individuals with autism and their families. The theme of this conference: "The Person with Autism Spectrum Disorders: Animating Hope" calls us to view autism in ways that may be new for many of us. In sharing community experiences from America, I will look at how – and whether – hope is being animated in our parish communities. Of equal or greater importance, we will consider the ways in which individuals with autism and their families are a source of hope to our beloved Church and to each of us.

The Inherent Dignity of Each Person

We are very blessed by the teachings and Tradition of our Catholic faith, which affirm the dignity of every human person, born in the image and likeness of God. The bishops of Latin America and the Caribbean, in their Fifth General Conference proclaimed, "that all human beings exist purely and simply by the love of God who created them and by the love of God who preserves them at every moment… the Lord is author and master of life, and human beings, his living image, are always sacred, from their conception, at all stages of existence, until their natural death, and after death. The Christian view of human beings makes apparent their value, which transcends the entire universe."[1] Saint John Paul II noted: "God has shown us unsurpassably how he loves all human beings, and thereby confers upon them an infinite dignity."[2] Further, His Holiness Pope Francis affirms that "to believe that the Son of God assumed our human flesh means that each human person has been taken up into the very heart of God."[3]

The question before us is whether individuals with autism and their families experience this dignity and love within their faith communities. Are they seen as of "inestimable value… masterpieces of God's creation, made in his own image, destined to live forever?"[4] Are they truly "willed… loved… and necessary"[5] as proclaimed by His Holiness Pope Benedict XVI? Do they find the open doors called for by His Holiness Pope Francis in *Evangelii Gaudium*: "The Church is called to be the house of the Father, with doors always wide open… Everyone can share in some way in the life of the Church; everyone can be part of the community, nor should the doors of the sacraments be closed for simply any reason."[6] Do we as Church leaders and pastoral ministers feel "impelled by mission to bring to our people the full and happy life that Jesus brings us, so that all human persons may live in accordance with the dignity given them by God?"[7]

The Diminishment of Hope

I encourage you to consider an important distinction between "inclusion" and "belonging" which has begun to be articulated in the United States. When people are "included" they are "allowed in" based on the goodwill of those in charge. There is the possibility of "exclusion" for any number of reasons including lack of preparation, budget concerns, fear, and disinterest. A sense of "belonging" on the other hand recognizes that "the Lord is God; he made us, we belong to him"[8] and that by virtue of our Baptism, we belong.[9] As a mother of a young woman with significant disabilities explained, "Before I read the bishops' Pastoral Statement[10] I thought that my parish offered our family three 'B's' – Baptism, back of the Church seating, and burial. But after reading the Pastoral Statement, I understood that the Church offered my family 'belonging.'" The statement referenced by this mother was written by the Catholic bishops of the United States in 1978. The profound truths of this and subsequent documents continue to touch hearts and direct our ministry with people with disabilities in dioceses throughout the United States.

Regrettably, many individuals and families are not finding such belonging in their parishes. In a brief survey conducted throughout the United States by the National Catholic Partnership on Disability (NCPD), countless stories were shared of pain and sorrow experienced within faith communities. Following are but a few of the answers shared regarding parish experiences of hurt or hopelessness:

"A parishioner with Asperger syndrome tried to join a lay religious group and was turned down. She has tried desperately to find a place to fit in and belong – unfortunately she is shunned by others."

"My son, who is on the spectrum, was trained and served as a Eucharistic Minister at our parish. When we moved to a new parish and he tried to volunteer his services, his attempts were criticized by some parishioners, based on not living up to certain standards within the parish."

"I attended Catholic school

from kindergarten through college, became a Catholic school teacher and administrator, yet there is not a place in the Catholic school system for my son."

"It is a sad experience when the pastor, priest or lay leaders place insurmountable obstacles in the way of families with children with autism spectrum disorders."

"The lack of a parish policy on inclusion in faith formation makes families feel hopeless."

"My family and I feel like we've been forgotten by the Catholic Church in general. We can build huge beautiful churches but we can't hire at least one special education teacher to work in our Catholic schools."

Many families reported the struggles they faced when requesting the Sacraments, and often they complained of having to drive long distances to participate in an accessible program. By far the most often shared "hurt" was the experience of stares and unfriendly looks received by parishioners as the family attempted to attend mass together. Others complained of isolation and shunning.

Several other ironic reflections were received in response to our request to share a best story of how hope was animated: "I wish I had some," "I have yet to experience this," "There is no hope in my parish."

In addition to these negative experiences encountered by many families and persons with autism there is a much larger threat to their dignity, and in fact, to their very existence – the scientific efforts currently underway to identify the genetic markers that would allow for the prenatal identification of autism. As we know, Servant of God Dr. Jerome Lejeune's ground-breaking discovery of the gene responsible for Down syndrome has led to the ability of the medical community to identify the syndrome prenatally, resulting in a current rate of abortion of between 80 to 90 percent. Dr. Lejeune, a devout Catholic, and the first President of the Pontifical Academy for Life did not anticipate, nor did he intend, his discovery to lead to such horrific consequences. We fear that a similar fate awaits those identified prenatally with autism.

Another perspective regarding research is expressed by some adults on the spectrum who resent funds being spent on research to "cure" them rather than on community-based supports and services, which would enhance their ability to participate in society. They note that "Research priorities should focus on areas that have the most potential to improve the daily lives of Autistic people, such as communication and assistive technology, best practices in providing services and supports, and educational methodologies."[11]

Hope Animated

Thankfully there is much more to the story. Hope is being animated throughout the Americas in parishes that recognize the gifts and potential of each person. When parishes are open to responding to the real and perceived challenges raised by parishioners with autism and their families, the gifts and graces of the Holy Spirit are poured out in countless ways. When the parishioner with autism is seen as a valued member of the community rather than a problem to be solved, the entire parish is blessed and experiences anew the infinite love of God.

The families and pastoral workers who answered NCPD's survey shared examples of positive experiences as well:

"Our son has always been welcomed by the choir director and members. There is always a place for him."

"The editor of our diocesan newspaper has a son with autism. Each week she features positive stories of individuals with autism and other disabilities, which is building awareness throughout our diocese."

"In our parish we experience people sharing their gifts of music and other talents."

"We accepted into our religious education program a young boy who had been rejected by another parish. On the day of his first communion he walked with his parents to receive Jesus for the first time. His dad looked over at me, with tears in his eyes. What a beautiful moment."

"Our parish hosted listening sessions from which grew ideas for improving ministry."

"Through adapted liturgies (both English and Spanish) whole families are returning to Church. One family said, 'Church is the only place we can go as a family.'"

"My son is 16 but mentally 2 or 3, on the autism spectrum, needs to be bathed, diapered, dressed and mostly fed... But his laugh lights the room and he has taught me the meaning of unconditional love, faith that there is a reason for all that comes to us, grace and the sanctity and glory of all life. Regular Mass was too much for him – the number of people, the volume of the singing, the length, the looks of disapproval for making involuntary sounds from the other parishioners...but we found the Adapted Liturgy at a parish in Portland, OR and we were forever changed. Once a month a special Mass is held – lights are low, singing and music are beautiful but not overwhelming, it is a small group of people – and most magically of all... our special loved ones can be themselves. If they speak out or yell or move strangely people smile and don't judge. We can celebrate difference and pray for strength without pity but with smiles. Garrett goes to this liturgy and SMILES – he lays his head quietly on my shoulder and just *is* and in that moment I know God is with us."

In addition, we are witnessing creative efforts and dedicated service on the part of many pastoral leaders to ensure meaningful participation in a life of faith.

Catechists and catechetical leaders are trained to meet the individual needs of each child. When preparing a child for the Sacrament of Eucharist, a catechist will work with the child to learn to distinguish between the Eucharist and ordinary bread.

Publishers are increasingly creating practical and beautiful tools, offering hands-on kits, catechist guides and website tips to help children on the spectrum attend mass and prepare to receive the sacraments. One kit for preparation for the Sacrament of Eucharist was originally designed by a young Boy Scout as part of his Eagle Scout project. This young man wanted to design a way for his sister with autism to be prepared to make her first communion.

Catholic universities offer courses of study to train future teachers and catechists to work with students with disabilities.

Numerous dioceses and parishes offer programs for individuals and sometimes families, including week-long camps, days of prayer, annual retreats, and respite evenings or days.

Throughout the continent, and indeed the world, L'Arche provides faith-filled homes while Faith & Light invites individuals with autism and other developmental disabilities, their families and friends into loving communities of faith.

In continents throughout the world, the Catechesis of the Good Shepherd is an approach to faith formation which engages all of the senses. The sacred environment, known as the atrium, is particularly suited for children on the autism spectrum as they grow in their relationship with God.

Needs and Priorities

More can be done to continue this process of animating hope in the lives of individuals with autism, their families, and our parish communities.

Acceptance

Many of these actions need neither a large investment of money nor the creation of new and involved programming. Rather, they require of clergy, seminarians, pastoral leaders and parishioners awareness and a deep commitment to accept those with autism and their families as brothers and sisters in Christ, recognizing their place within the Body of Christ.[12] We must follow the admonition of the U.S. Catholic bishops in their 1978 *Pastoral Statement*, "We call upon people of good will to reexamine their attitudes toward their brothers and sisters with disabilities and promote their well-being, acting with the sense of justice and compassion that the Lord so clearly desires. Further, realizing the unique gifts individuals with disabilities have to offer the Church, we wish to address the need for their integration into the Christian community and their fuller participation in its life."[13] The bishops also noted: "For most Catholics the community of believers is embodied in the local parish. The parish is the door to participation for individuals with disabilities, and it is the responsibility of the pastor and lay leaders to make sure that this door is always open."[14] The bishops of Canada further affirmed, "The emerging and growing sensitivity of the parish community to all its members, including the disabled, opens many new liturgical doors for authentic worship… The ministry of the disabled to, for and with the praying parish community is one in which the beautiful uniqueness of all is celebrated. The special gifts of all, including the disabled, help a chorus of praise and thanksgiving rise to the God of all life." [15]

Support for Families

Every parish has families that include members with autism, and their presence holds significant implications for the New Evangelization.

We must acknowledge the emotional trauma that families encounter when a child has been diagnosed with autism. Having anticipated a healthy, happy child, parents encountering a diagnosis of autism now face a life-changing reality. At this moment the parish community has the opportunity to respond to this pain in a Christ-like manner. How the parish responds determines whether that family will feel embraced by the community, or cast out to cope alone.

Following is a brief reflection from a mother describing some of the stresses experienced by her family:

"My experience with disabilities was very limited prior to having Danny. The family dynamic when you have a child with autism is impacted greatly. To say that there's a lot of stress would be a tremendous understatement. You know, there is always a balancing act when you have four children or any number of children that's more than two. Right now Danny's friends and peers – well, his friends are few, very few and that's a very painful part of being a parent of a child with autism. Our experience at mass now as a family is much better than it was when he was younger. Our experience with mass with Danny was actually a very big problem and it caused a huge stress on my husband and me. He would act out and draw attention to himself at mass and my philosophy was 'we have to stick it out, we can't remove him from church every time he acts out because then he's getting exactly what he wants.' My husband and I didn't agree but we did find a way to compromise and we started out by having him many times stand in the back of the church and if he got through a certain amount of time behaving that way you know then we kind of just kept taking little steps at a time until he was finally able to sit in mass and not act out."

Pro-active Parish Practices

I am pleased to report that a great number of parishes are taking pro-active steps to welcome and embrace persons with autism and their families. An important first step is developing awareness on the part of the parish community about the unique characteristics of persons with autism and issues they and their families face. Providing accurate and understandable facts about autism to the parish community helps to alleviate fears that may arise and promotes understanding of the characteristic behavior exhibited by persons with autism. I have witnessed several effective ways that parishes seek to raise awareness about autism: (a) conducting educational workshops on autism open to the entire parish community; (b) specifically including autism in prayers of the faithful at mass; (c) developing pew cards detailing facts about autism and the challenges faced by individuals with this disability; (d) articles in the bulletin, and most importantly (e) inviting persons with autism to share their story with their faith community.

In many dioceses and parishes, faith formation policies are being developed specifically to address the unique learning styles of persons with autism, as well as programs for preparation of the Sacraments. One such program involves employing peer mentors that journey with their teen counterparts with autism who are participating in faith formation activities. Parents are included in the program, meeting together in prayer and support. Parishes likewise provide needed accommodations to enable active participation, including, but not limited to, physical access to the church, sanctuary, and other parish facilities, sign language interpreters, Braille and large print resources, and adequate lighting.

Another critical piece to ensuring pro-active parish practices is that of training staff who will interact with persons with autism and their families, which really includes all parish staff and volunteers. I once was conducting training for staff at a parish in my archdiocese that has exceptional outreach and support for their members and families with disabilities. In the midst of my talk, I was asked by the pastor's administrative assistant why this training was even needed given that the parish was already doing a good job. I turned to the pastor for a response, and he paused and then answered, "I don't want people with disabilities and their families to hear 'no' from our parish. Our staff needs to be prepared. We need to say 'yes.'"

Animators of Hope

Clergy, religious, seminarians and deacons play an essential role in animating hope. Through homilies and pastoral support they can enliven the parish with a spirit of welcome and belonging, following the witness of our Holy Father Francis who demonstrates over and over his caring and love through his prophetic example, words and actions. By modeling such an attitude of welcome and belonging for our faith communities throughout the Church, priests, religious and deacons are leading by their example in ways that will further the acceptance and embrace of persons with autism and their families.

More importantly, we need to recognize and affirm people with autism as animators of hope for their families and our communities, "called to exercise the mission which God has entrusted to the Church to fulfill in the world, in accord with the condition proper to each."[16] They demonstrate the wisdom proclaimed in 2008 by His Holiness Pope Benedict XVI in an address to young people with disabilities in the United States: "God has blessed you with life, and with differing talents and gifts. Through these you are able to serve him and society in various ways. While some people's contributions seem great and others' more modest, the witness value of our efforts is always a sign of hope for everyone….God's unconditional love, which bathes every human individual, points to a meaning and purpose for all human life."[17] They reflect the truths shared in the 2005 *National Directory for Catechesis*: "All persons with disabilities have the capacity to proclaim the Gospel and to be living witnesses to its truth within the community of faith and offer valuable gifts. Their involvement enriches every aspect of Church life… They are not just the recipients of catechesis – they are also its agents… Every person, however limited, is capable of growth in holiness."[18]

Many here may have never experienced people with autism in this way. We often fail to consider another person's gifts, particularly if they are nonverbal or their disability is significant.

One such person who lovingly shares his gifts and light is Larry Thompson, son of my colleague, Dr. Nancy Thompson. Larry is on the autism spectrum, and is one of the oldest living persons with a rare genetic condition causing multiple congenital anomalies, intellectual disability and fragile health. He is a faith-filled Catholic who has served in his parishes over the years as an altar server, greeter, usher, and now as an extraordinary minister of the Eucharist. He has befriended the bishops of the dioceses in which he has lived, and has a special ministry of praying for bishops, cardinals and our Holy Fathers. Larry is a 2nd degree Knight of Columbus, and enjoys the fellowship and service shared with his fellow Knights. Nancy was told by a young couple from one of their parishes that they were tempted to have an abortion when advised to do so by their doctors because of the poor pre-natal diagnosis they had received. Then they remembered Larry at Mass and his happy family and that gave them the courage to refuse the abortion and give birth to their baby. Larry's gifts and Christ-like light saved that baby's life.

Another young man with more significant disabilities animates hope among his family and friends. His mother recently shared the following reflection with me: "I am a blessed mother of a beautiful nonverbal child with profound autism and adolescent onset seizures. He is my light and my inspiration. When faced with the challenges of autism I will not despair. Isolation, financial burden, and the utter lack of help are met with hope. Hospital bedside prayers gave me strength. Gratitude gives me comfort and every day is a gift. Faith is my salvation and my life is joyful. I don't presume to know God's plan for me and am in awe of his guiding hand along my path."

I would like to conclude with the transcript of a video clip of a young adult with autism, Danny, who shares his thoughts on faith and his love of God. Also featured is Danny's mother, Loretta, who was quoted above under "Support for Families."

Transcript of video clip:

Danny: I like to read. I like practicing the piano. I play sports like basketball and baseball, hockey. I like to serve, I like to receive communion at Mass.

Interviewer: Are people friendly to you at church?

Danny: Yes.

Interviewer: What do people say to you when they see you at church?

Danny: Hi.

Loretta: The gifts that Danny brings us are many. He is just a really nice person, he's a gentle soul, he shows us a lot of love. He teaches us how to love when it's difficult. Danny has on occasion sung at mass and there have been some very special moments at church.

Interviewer: Is there anything else about Mass that you really like?

Danny: I like to serve, I like to, I like bread.

Interviewer: Do you like to receive communion, is that what you're trying to say?

Danny: Yeah, I like to receive communion at Mass.

Interviewer: What do you say to God for help?

Danny: God, I need help.

Loretta: I really think that he wouldn't be so willing and actually outspoken about his desires to go to church and go to religiously-oriented events and to be willing to say the rosary and to do those kind of things if he wasn't somehow feeling the love of God and the love of his family because of our faith.

Loretta: My faith to me is a source of strength and comfort. That's really it in a nutshell. Without it, I can't even imagine what life would be like.

Danny: I like to receive communion at Mass, I like to go to mass, just to pray in the tabernacle, for God.

Thank you for this opportunity to speak with you today. May God bless all of our efforts to build his kingdom.

Notes

[1] V General Conference of the Bishops of Latin America and the Caribbean, *Concluding Document, Aparecida* (13-31 May 2007), 388.

[2] John Paul II, Message to the Handicapped, Angelus (16 November 1980): *Insegnamenti*, 3/2 (1980), 1232.

[3] Pope Francis, Apostolic Exhortation *Evangelii Gaudium* (24 November 2013), 178.

[4] Pope Francis, *Message from Pope Francis to Catholics in Ireland, Scotland, England and Wales* (17 July 2013).

[5] Pope Benedict XVI, *Inauguration Homily* (24 April 2005), 6.

[6] *Evangelii Gaudium*, 47.

[7] *Concluding Document, Aparecida*, 389.

[8] Psalm 100.3, *New American Bible, revised edition,* Confraternity of Christian Doctrine, Washington, D.C., 2010.

[9] *Code of Canon Law: Latin-English Edition*, c. 204, §1, Washington, DC: Canon Law Society of America, 1983.

[10] United States Conference of Catholic Bishops, *Pastoral Statement of U.S. Catholic Bishops on Persons with Disabilities* (16 November 1978), Washington, DC.

[11] Autistic Self Advocacy Network, *Position Statement – Services and Supports*, posted at http://autisticadvocacy.org/policy-advocacy/position-statements.

[12] Center for Applied Research in the Apostolate, *State of Ministry in the U.S. Church for People with Autism and Their Families*, Washington, DC (2011).

[13] *Pastoral Statement,* 1.

[14] *Pastoral Statement*, 18.

[15] Canadian Conference of Catholic Bishops, *At Worship with the Disabled* (2002).

[16] *Code of Canon Law*, Can. 204 §1.

[17] Pope Benedict XVI, *Meeting with Young People Having Disabilities*, St. Joseph Seminary, New York, (19 April 2008).

[18] United States Conference of Catholic Bishops, *National Directory for Catechesis*, Washington, DC (2005), 49.

4.3 The Spirituality of Persons with Autism

**PROF. DR.
ARNDT BÜSSING, M.D.**
*Professorship of Quality of Life,
Spirituality and Coping,
the Institute of Integrative
Medicine,
the Faculty of Health,
Witten/Herdecke University,
Germany*

Scientific research has proved that belief in God requires cognitive processes. Moreover, several dimensions of the complex construct "spirituality" indeed refer to circumscribed cognitive aspects (i.e., belief in specific doctrines, sophisticated understanding of theological interpretations, the intellectual search for meaning in life), which are defined with the emotional aspects of "spirituality" (i.e., unconditional confidence, compassionate love, joyful hope).

Neuroimaging studies show that thinking about God and praying to God activates brain regions involved in mentalizing (Kapogiannis *et al.*, 2009; Schjoedt *et al.*, 2009). This mentalizing refers to a person's empathy, i.e. perspective taking, interest in other people's beliefs and desires, and understanding emotions. Findings indicate that "praying to God is an inter-subjective experience comparable to 'normal' interpersonal interaction" (Schjoedt *et al.*, 2009). It is an interesting fact that praying is represented in the same parts of the brain as talking to friends. In fact, praying to God means talking with God (Norenzayan *et al.*, 2012).

However, in persons with autism empathic mentalizing seems to be different. Autistic participants were only 11% as likely as neuro-typical controls to strongly endorse God – and this effect was unrelated to their IQ (Norenzayan *et al.*, 2012).

Moreover, higher autism scores predicted lower belief in God, and this relationship was mediated by mentalizing (Norenzayan *et al.*, 2012). One may argue that belief in God is related to greater religious involvement which may increase mentalizing. However, religious attendance by itself did not eliminate the effect of mentalizing on belief in God (Norenzayan *et al.*, 2012).

Findings from Qualitative and Empirical Studies

So far, we do not know too much about the place of faith in the lives of people with autism. While there are several theoretical reflections and moral imperatives, less is known about the faith practices of persons with autism, with intellectual and developmental disability (IDD), in their *own* words. In fact, there are only a few studies which describe religious identities, congregational involvement, and spiritual expression in persons with IDD.

Liu *et al.*(2014) qualitatively analysed the expressions of faith in 20 young people with intellectual disability from the USA They found that participants talked about a number of activities related to (a) personal prayer, (b) beliefs and behaviour, (c) congregational activities, (d) rites of passage, (e) social connections, (f) ministry to others, and (g) other expressions. The authors stated that "although some of these expressions were unique, most reflected some common ways in which young people without disabilities express their faith" (Liu *et al.*, 2014) as well. Many of these young people with intellectual disability discussed how their faith community had been a positive influence in their lives, as they found it to be: (a) a place of belonging and (b) where people are good to them. In addition, they also discussed how their faith had been a source of (c) help, (d) friendship and love, (e) healing, and (f) protection (Liu *et al.*, 2014). Several stated being known and understood by God; others addressed how they had come to a stance of acceptance as regards their disability.

"He put Asperger's in my life for a reason and I am wonderfully and perfectly made. And it was His choice. That I should understand it's a part of me and I can't do anything about it, but all I have to do is …if I need help, ask Him." (Liu *et al.*, 2014)

Others viewed their disability as their strength or a gift to be used, while some saw their disability as a condition to be healed or relieved.

"I want to know what it feels like to not have autism. I wish I – I want to figure out, I want to be able to see how I would be if I didn't have the…if I didn't have Asperger's." (Liu *et al.*, 2014).

In contrast to these rather positive experiences in qualitative studies, empirical studies indicate a meaningful problem: Children with autism were significantly less likely to attend religious services, more likely to miss school, and less likely to participate in organized activities (Lee *et al.*, 2008). Moreover, Hanlon reported about the experiences of 58 parents of children with special needs (among them 41% with autism). They felt that their child had a negative experience in their community (68%), was excluded from activities within their spiritual community (53%), and that they considered switching spiritual communities because of experiences related to their child (38%) (Hanlon, 2014).

What about the situation in more secular Europe? Are persons with autism in Germany also connected with a faith community, are they praying to God, and do they see their faith as helpful in dealing with life's concerns?

Our studies have shown that adolescents or young adults have low scores on religious orientation, but score high on relational spirituality (Büssing *et al.*, 2010). Among them, 67% intellectually regarded themselves as neither religious nor spiritual (Büssing *et al.*, 2010). Similar findings can be shown in adults with chronic illnesses, i.e. patients with chronic pain illnesses showed rather low religious trust, and were less engaged in religious practices (Büssing *et al.*, 2009). Among them, 42% would intellectually regard themselves as neither religious nor spiritual (Büssing *et al.*, 2009). Moreover, 50% of patients with multiple sclerosis and psychiatric disorders regarded themselves as neither religious nor spiritual (Büssing *et al.*, 2014). Thus, we have to consider a relatively large proportion of individuals who do not regard themselves as religious, and therefore also the secular and relations facets of spirituality have be involved.

Findings from a Pilot Study among German Persons with Autism

To address the dimension of spirituality in persons with (Asperger) autism, we started a pilot study with a standardized questionnaire enrolling four adolescents and three adults. These first data are neither representative nor valid for the drawing of reliable conclusions. Yet they give an impression and are suited to the generation of hypotheses for future studies.

Three out of seven persons with Asperger autism of this pilot study believe in God, two are unclear about this, and two do not believe (Table 1). Six of them pray sometimes and go to church sometimes, even though not all believe in God. Feelings of gratitude and the experience of beauty in life were reported more often in adult persons. Among the adolescents, gratitude was experienced often in the two who believe in God. Although six out of seven persons preferred to be alone, they nevertheless related to others (from a distance) as they consider the needs of others and help when their help is needed (Table 1).

With respect to their psychosocial and spiritual needs, finding private "inner peace" was of greatest relevance (Table 2). Direct contacts to talk with others so as to obtain release from fears and worries (which thus may contribute to feelings of inner peace) were of some relevance for four persons. Yet, talking with others about the less concrete question of meaning in life was of relevance only for two adult women and for one 11 year-old boy (Table 2). Both items address social interactions which are problematic for most persons with autism. Forgiveness was of strong relevance for one boy and one woman – both believe in God and are therefore assumed to be religious.

More specific religious needs were the need to turn to God which was of relevance for two of the three believers. The need for private prayers (which mean communication with God) was of rel-

Table 1: Experiences and practices (modified items derived from the SpREUK-P questionnaire)
Scoring: 0 – never; 1 – seldom; 2 – often; – 3 very often

Experiences / Practices (0-3)	11 y male	15 y male	15 y male	17 y male	37 y female	40 y female	54 y female
Belief in God	yes	yes	no	don't know	don't know	yes	no
I prefer to be alone	1	**3**	2	**3**	**3**	2	2
I reflect upon the meaning of life	2	**3**	1	**3**	2	2	2
My thoughts are with those in need	2	**3**	1	1	**3**	2	1
I help others when they need me	**3**	**3**	2	1	1	2	2
I have had positive experiences in my life	1	1	2	1	2	**3**	2
I have feeling of great gratitude	2	2	1	0	2	**3**	2
I have feelings of wondering awe	1	2	1	0	2	1	1
I pray	2	2	0	1	1	1	1
I go to church	2	1	1	0	2	2	1

Table 2: Psychosocial and Spiritual Needs (items derived from the SpNQ questionnaire)
Scoring: 0 – none; 1 – weak; 2 – moderate; – 3 strong

Psycho-social and Spiritual Needs (0-3)	11 y male	15 y male	15 y male	17 y male	37 y female	40 y female	54 y female
Belief in God	yes	yes	no	don't know	don't know	yes	no
The need to …							
Find inner peace	2	**3**	2	**3**	**3**	**3**	1
talk with others about fears and worries	**3**	1	1	2	2	**3**	1
talk with someone about the question of meaning in life	2	1	0	0	**3**	**3**	1
pray	2	0	0	0	2	-	0
Turn to God	**3**	0	0	0	1	2	0
forgive someone (i.e. someone who has not treated you right)?	1	**3**	0	0	0	2	1

evance only for one "undecided" woman, and the 11 year-old boy (Table 2). This finding fits with already existing data that only a few persons with autism would strongly endorse God (Norenzayan *et al*., 2012). Moreover, these preliminary findings indicate that what they do "sometimes" (praying or going to church) is not necessarily that what they would wish for ("need").

The intention to have someone at your side who cares for you was of relevance particularly for the adolescents, but surprisingly not for adults (Table 3). A further, more explicit, topic refers to the need to turn to someone in a loving attitude. Here, all four boys had this need, and one woman. Also these needs have to be seen in the context of deeper relations which are often problematic for persons with specific forms of autism – or not wanted at all (Table 3).

Table 3: Relations with others (items derived from the SpNQ questionnaire)
Scoring: 0 – does not apply at all; 1 – does not truly apply; 2 – don't know (neither yes nor no); 3 – applies quite a bit; 4 – applies very much

Psycho-social and Spiritual Needs (0-3)	11 y male	15 y male	15 y male	17 y male		37 y female	40 y female	54 y female
The need to...								
have someone at your site who cares for you	**4**	3	**4**	3		0	1	0
turn to someone in a loving attitude?	**4**	**4**	**4**	3		1	3	1

These first findings should be specified by data from a structured interview with a 37 year-old woman with autism. She said that she would not regard herself as religious anymore because of her difficulties in "understanding" the beliefs and doctrines of the Catholic Church. Moreover, she felt that she has to disavow herself in order to follow these concepts which she had difficulties in believing in. Nevertheless, she is still attracted by churches and is highly moved when watching people in deep prayer. Because of her problems with the Catholic Church, she started practicing Zen meditation for some time. Yet, the "superstructure, also several texts about it…rather discouraged me. Because I didn't understand what I had read…It was too restrictive for me, too much self-denial; and always the claim to go beyond my own limits." This means she was discouraged by the structures, doctrines, and expectations. "Preferably I would like to ignore this superstructure, and simply sit on my cushion and practice silent meditation." For her, pure practice seems to be more concrete but she is nevertheless emotionally attracted to those who pray.

Support by the Faith Community

Although studies indicated that faith is an important resource for US parents, a recent study among 416 parents found that "parents generally were not satisfied with the level of support provided by faith communities, and they highly valued a welcoming and supportive attitude by the community" (Ault *et al*., 2013). The above described woman with autism felt uncomfortable with the mediation group, too, because she felt an implicit demand to become a different person to her actual self.

The above-described first findings of the pilot study indicate that specific religious topics are of relevance for several persons with autism, but not for all. In particular, the secular need for inner peace was of importance for most of them – similarly to the more general population (Büssing *et al*., 2013). This topic can, but must not, have a religious connotation. Yet, one may regard it as a low threshold option to support the needs of persons with autism. Meditative approaches to find stability and inner peace with the option of a supporting community (i.e., contemplation, singing, praying etc.) might be an option, but without the pressure of specific doctrines or creeds which would increase their insecurity and fear.

First of all it is important to acknowledge that autism is not an illness to be "cured". These individuals are "good" and "of value" as they are. Rather, there is the need to approach persons with autism differently – more openly and according to their specific needs and abilities. What is required is an attitude of listening rather than knowing what is best. Whatever we do, it should be an invitation to open the "inner doors" towards the Sacred, within the rich body of spiritual practices of our Church as well. Despite an obvious decline of pastoral workers (and often also of social activities within local faith communities), *Caritas* has always been a matter of lay persons who take responsibility for social (and maybe also pastoral) initiatives as well. We all are the caring and compassionate community of faith which is the Church. ■

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Conclusions and Recommendations

DR. ROSA MEROLA
Psychologist, psychotherapist, expert penitentiary consulting psychologist,
the Ministry of Justice, Italy;
Consultor of the Pontifical Council for Health Care Workers

In a society that is highly specialised and technocratic, for the scientific community, for families and for health-care workers who take responsibility for autism spectrum disorders (ASD), the complexity and the heterogeneity of such disorders still constitute a challenge today, given that, as we have heard form the distinguished speakers at this international conference, this is a complex and chronic disturbance which is hereditary in its transmission that is polygenic in character. The ASD condition is characterised by an early multimodal aetiopathology of the central nervous system that causes complex disability and attacks in a pervasive way in the individual involved communication, behaviour and socialisation.

Thus to achieve goals of high quality we need an early diagnosis and a systemic response, that is to say an integrated and personalised approach for the whole of an individual's lifespan in the case of the patient and in that of his or her family who have the right to be defended by an ethical commitment of society to understanding and dealing with their needs and potentialities in an effective way in a climate of respect for frailty, of acceptance, of fairness and of certainties – these are guarantees for a positive dynamic process that is practical, developmental and inclusive both at a personal and social level, as is recommended by the resolutions of the United Nations and the World Health Organisation, as well as by the legislation of individual countries.

On the basis of what has emerged from the deliberations of this international conference, after an examination of the essential priorities on which the operational policies highlighted here by the whole of the national and international scientific community should be directed and coordinated, and having to translate theory into practice in order to improve the integration of inter-sectorial activities at the level of care and treatment (health care, schooling, social life, work), the following conclusions and recommendations are hereby outlined:

1) The promotion at a national and international level of *scientifically correct information and social sensitisation* in order to break down psycho-cultural barriers and defeat stigma and marginalisation through the organisation of events, media campaigns and other initiatives; the drawing up for autism spectrum disorders of a *Charter of Services and Rights of Patients and their Families*.

2) The sensitisation of political interlocutors in order to achieve *a uniformity of approach* in essential care levels for ASD, together with the greatest guarantee of stability and continuity of human, instrumental and financial resources, with the promotion of international cooperation, with governments and non-governmental agencies, in order work against – in particular in the poorest countries of the world – inequalities, limited infrastructures and a shortage of services which are available only to a few people.

3) The organisation, after a speedy diagnosis, of mental and pastoral therapeutic initiatives to support the couple and the whole of the family unit: these are wounded bearers of parenthood that should be involved as active partners in the holistic treatment of their relatives with autism spectrum disorders and supported economically by society in order to assure access to care and treatment that is too expensive as well as a future for their children that will reassure them as regards the troubled and dramatic question – 'who will there be after us?'

4) The creation within the framework of neuropsychiatric services (minors/adults) of *specialist ASD teams* for the establishment of inter-sectorial care plans (schooling, families, work, social centres) in order to assure therapeutic linearity and continuity for the functional profile of the patient.

5) The establishment at a university level of *training* and professional refresher courses of a *specific and ethical* character of all the professional figures that help people who have autism spectrum disorders.

6) The strengthening of biomedical, clinical and epidemiological research: priority should be given to genetic research and research into toxic or infective environmental factors which seem to play an important role in the genesis of autism; and in the same way a development of research in the field of special psychology and social pedagogy in order to develop psycho-educational strategies that are more effective in the sector of schooling, which is a relevant part of the educational project for the development of the relational potentialities and capacities, as well as the adaptation and the autonomy of individuals with autism spectrum disorders.

7) The adoption of urgent policies in order to *implement practicable and shared guidelines* for the individualised establishment of diagnostic, therapeutic, educational and social-care pathways, with especial attention being paid to cases of psychiatric co-morbidity, and also for pharmacological treatment, the employment of which, in addition to referring to medical deontology, should be applied in a way that respects the four basic principles of contemporary clinical bioethics (being beneficial, not causing harm, autonomy and justice), and *only after* every other attempt to adapt

the environment and the individual programme has been shown to be ineffective.

8) The activation of screening programmes and the institution of registers starting with nursery schools (0-2 years), with the involvement of general paediatricians *for the early identification of cases at risk* and the indication of multi-specialist teams for childhood and adolescence which will follow the whole of the diagnostic pathway for children that are neuro-diverse.

9) 'The formation of a network' at an international level for the purposes of scientific cooperation for those working in the field and at a national level as a reference point that can be used by services and families for the identification of the qualified ASD centre of the local area that is nearest to them and to which reference can be made in emergencies.

10) *The creation of ASD specialisation districts* and social centres and daily operational units coordinated with hospitals, associations of parents and Catholic or lay associations of volunteers, to welcome, support and promote care both for the integration of the patient through processes of formation/integration at the level of work and recreation and for the family, relieving it of the hard work and the suffering of daily life and improving its quality of life.

11) A reassessment in this area of the role of the Churches and local organisations and agencies in order *to activate a catechesis that enables people with autism spectrum disorders to receive the sacrament of the Eucharist*, giving pastoral care new impetus as regards the gospel message: the certainty of belonging to the people of God and participating with the family, Body and Spirit, in Holy Masses.

In contemporary modern society which boasts civilisation and progress, which refines and exaggerates the mass media, falling, in a paradoxical way with excesses in terms of self-reference, into an incommunicability in relationships *where appearing to be is worth more than being*, *examining the aspects, the critical points and the excellent features of every operational reality in the world, whether secular or Catholic, private or public, means to look for its professionalism in order to assure the ethical character and high quality of the services that are provided by each country*. But above all it means *motivating consciences, emphasising the humanity of care and treatment, and accessibility for everyone without forms of discrimination*.

It means, as Pope Francis has exhorted us, to develop interior values and growth to 'become neighbours', respecting each other, in which the role of self-giving for everyone (health-care workers, patients, families) is an important element of care and treatment itself, of service and the relief of suffering of other people – the engine of that culture of encounter and of welcome which in particular in the vulnerability of the suffering person, in the intrinsic acceptance of his or her frailty, makes each one of us discover our need for a spirituality which ignites faith, illuminates our journey, and provides courage and consolation to our hearts. *It animates Hope in Christ*, that Hope that does not disappoint and is capable of a renewed proclaiming of the Gospel that takes us back to the centrality of the person and his or her dignity in order to promote a human, supportive and shared culture – 'community care' that goes beyond taking responsibility for and becomes *'taking care of the other with primary respect for his or her transcendence'. This is true Christian witness to the Civilisation of Love and Life.* ■

Final Observations

PROF. MASSIMO PETRINI
Dean of the 'Camillianum'
International Institute
for the Theology of Pastoral
Care in Health,
Rome

The international conference of this year organised by the Pontifical Council for Health Care Workers (for Health Pastoral Care), the twenty-ninth in its history, has been dedicated to 'The Person with Autism Spectrum Disorders: Animating Hope'.

This is a further confirmation of the commitment of the Pontifical Council which is always directed towards drawing up, and then introducing into a reality that has been attentively studied, care and pastoral initiatives. Indeed, this conference, which took place on 20-22 November in the Hall of the Synod in the Vatican witnessed, as will be observed, the participation of specialists from various ecclesial and scientific fields, but also the participation of a very numerous and international audience which followed the deliberations of the international conference attentively – deliberations, for that matter, which took pace throughout the day.

This pathology, autism, with the participation of Italian and foreign specialists, was examined in its clinical, psychological, psychiatric, educational, spiritual and familial aspects because, as is the case with every other pathology, family life is deeply influenced by it.

This is a pathology that is still mysterious. Some pathologies have evident physical signs and the diagnosis can be carried out before the disorder manifests itself, and without understanding its nature. Autism, in opposite fashion, does not have these signs and its nature has to be understood to carry out a diagnosis as soon as possible and with as much precision as possible.

Autism is not a modern phenomenon. Even though it has been recognised only in recent times. If one considers the short history of psychiatry, and the even shorter history of child psychiatry, it is well known that a disorder described recently is not necessarily a recent disorder. For a long time the first presumed demonstration of autism was its description by a pharmacist at Bethlem Hospital, the psychiatric hospital of London. This concerned a boy aged five who was admitted in 1799. In particular, it was observed that this child never played with boys of the same age and did not become affectionate towards them but, rather, played in an engrossed and isolated way with toy soldiers.

One can observe that the excess of autistic boys as compared to autistic girls is 4 to 1 and that individuals with autism can have other disorders, for example attention deficit disorders, movement disco-ordination disorders, and language and dyslexic disorders.

One merit of the international conference is that of having organised a meeting of international experts as well as of having brought out this problem from a narrow specialist domain and subjected it to the attention of broader public and ecclesial opinion.

During the two days of debate, to epidemiology were added the contributions of research, prevention and therapies, diagnosis and pharmacological treatment, but also the psycho-socio-cultural, educational, theological and pastoral aspects – these are all aspects that are absolutely necessary in treatment of this pathology but which it is difficult to address and consider all together at one scientific symposium.

This was a debate which confirmed the complexity, starting with diagnosis, which marks out this pathology, and the need for a therapy that must involve pharmacological treatment together with educational, psychological and psychiatric action which lasts over time.

But although, naturally enough, to speak about early diagnosis means speaking about children, one should make clear, as in fact was done during the international conference, that adults can be autistic as well. Indeed, the conclusions brought out that mental disability, like autism, will not disappear, despite the advances in adaptation and positive changes in behaviour. Nonetheless, people with autism can compensate for – and often this is something that they do – their disability in a notable way.

These people must, therefore, be directed towards social roles in which their qualities are taken advantage of. The processes of adaptation and learning are active throughout these people's lives and can always be available to bring about a change.

And this naturally calls upon the responsibility of a society which, as H.E. Msgr. Zimowski pointed out, was called by Pope Francis in his recent apostolic exhortation *Evangelii gaudium* to pay attention so as to be near to new forms of poverty and frailty, in which we are called to recognise the suffering Christ, even though this apparently does not lead to tangible and immediate advantages (cf. n. 210).

This international conference, therefore, has been a further initiative of the Church in the world of health and health care, the theological *locus* in which the Pontifical Council for Health Care Workers works at an international level, but an initiative which, like the previous international conferences, as has been said, has witnessed a care and pastoral intervention based upon an accurate analysis of reality.

But attention was laid in particular, as has been pointed out, on the reality of the family, and this from two points of view. First, to emphasise the burden of care of the family, for that matter a co-actor in the therapy, which is very often forced to bear the financial burden of a therapy that continues over time which, indeed, often falls upon the family, in countries where there is a national health system as well. All this was done without underestimating the suffering that this pathology causes within the family unit which engages in a desperate search for an alphabet by which to communicate with one of its members – the child who was born with so many expectations felt by his or her parents.

The second element in considering the family and the person of the autistic person was, during the third day, the meeting dedicated to families, therapists, priests, men and women religious, as well as associations and volunteers, with the Holy Father Pope Francis.

This was a meeting where, as H.E. Msgr. Zimowski has written, specifically because of the notable therapeutic contribution offered by music to this specific pathology, it was thought helpful to take on the form of a party, thus making easier the involvement and participation of people, as a sign, as well, of the concern, the nearness and the solidarity of the Church community.

One final observation: the proceedings of this international conference, as is always the case, will be published in the review of the Pontifical Council, *Dolentium Hominem,* and this will allow access to the papers and the conclusions by a very large international public. ■

Conclusion of the International Conference on People with Autism Spectrum Disorders. The Psycho-affective Relationship with the Autistic Child

MSGR. TONY ANATRELLA
Psychoanalyst and specialist in social psychiatry,
Lecturer at the College of the Bernardins and
at the Free Faculties of Philosophy and Pedagogy, Paris, France;
Consultor of the Pontifical Council for the Family and
of the Pontifical Council for Health Care Workers

Introduction

As we have heard during this international conference on autism spectrum disorders (ASD), the question of cognitive reawakening and the affective lives of children is a determining aspect as regards the relationships that their parents and their environment should develop with them. Most of the educational and therapeutic efforts that are engaged in seek to establish peaceful ties with the child in order to reach him in human terms at the level of his possibilities. The parents play an essential role and thus they must be supported and valued in the position they hold: they could wrongly blame themselves and believe that they are incompetent. They remain the first educators of their child and the various medical doctors who act as therapists are at the service of the parental relationship and the reawakening of the child, within, however, the limits of what can be achieved.

By way of a conclusion and recommendations, I would like to clarify their outlines starting from what emerged during our days of work.

1. Some Essential Aspects

The international conference on the autism spectrum that was held in Rome on 20-22 November 2014 under the aegis of the Pontifical Council for Health Care Workers was unanimously appreciated for its high scientific quality. Researchers and medical doctors who are some of the most esteemed and recognised at an international level for their academic knowledge and their clinical experience came together to inform each other about the state of their research and the therapeutic and educational activity in which they are involved. They came from all over the world and belong to different cultural climates.

It is important to emphasise the specific interest of this international conference which took into consideration all the fields of research, ranging from the neurosciences to genetics, psychiatry, psychoanalysis, nutrition and the various complementary and educational therapeutic approaches. It also studied the primary role of parents and of the various associations that provide pedagogic help to autistic children. Our analysis went as far as the theological and spiritual dimension in order to locate in a better way the experience of God that these children and adults can have and to identify the pastoral approaches that should be implemented with them. In this area a prayer drawn up by one of them was especially important and also extremely illuminating for those taking part in the international conference. The papers amply demonstrated this overall vision of autistic children which takes into account all their interests. Nobody should be excluded.

It was especially striking to observe how most of the people who gave papers place the autistic child and his or her family at the centre of their work. Our international conference experienced this and this must be *a principal recommendation: the parents are not only the first educators of their child – they are also the first observers of what he is experiencing*. As privileged observers they know how to identify the anomalies that are expressed in the attitudes and behaviour of their child who seems to be indifferent after a number of months and even years. In addition, they are the first to ask for a professional opinion in order to understand what is happening (the diagnosis), to obtain a prognosis and to take into consideration therapeutic and educational measures. *The role of specialists is a second recommendation and involves supporting them in their educational role and their proposing of various therapies and educational measures* which have been described in various texts in the literature in the field. The parents themselves often look for alternative therapies, some of which can produce interesting results, whereas others are not to be recommended. At the same time, as was said, some methods are of varying degrees of efficacy depending on the individuals involved: they will thus be valid for some autistic children and not for others. It is thus difficult to provide a universal response. The response must always be adapted and adjusted to what people experience. In this sense, we must demonstrate creativity and continue with our therapeutic and educational research and provide proof of their positive results.

This international conference was marked out by an attempt at analysis and creative intellectual contributions but also by a wealth of sensitivity and emotions during the papers and the testimonies. This, in fact, brought out how much those who live (parents) and work (researchers, medical doctors and educators) with autistic children are obliged to develop a sensitivity that allows them to be in contact with their emotions in order to recognise in a better way what these children may live in their forms of closure, silence, fear and violence. One could perceive the emotions of the speakers when they cited ways of assessment that were transformed into action or questions and ideas that are formulated by these young autistic people. These last, *and this is the third recommendation*, are able to develop exceptional capacities, thus bringing out aspects of our humanity which we might not understand without them.

We should thus remember that these autistic individuals do not learn in the same way or with the same ease as other children. In numerous cases of ASD we are not necessarily in the presence of a mental deficit but, rather, we are in the presence of neuronal microcircuits which in the brains of autistic children are thought to be hyper-functional. They perceive everything in a very intense way and thus every sensation is notably increased. In order not to add irritation or excitement these children should not be over stimulated. An environment that is as calm and serene as possible is advised. Once the parents understand this phenomenon and adapt to it as a consequence, they have a better idea of what they should do in order to reassure their child. Evidently enough, this will require from them a great deal of time, energy and patience.

The question of the origins of autism is still uncertain and the research in the field, as the various papers and contributions made clear, has formulated some hypotheses as to action to be taken but these still have to be confirmed. In some forms of autism we encounter genetic problems even though one should not reduce this phenomenon to a single gene. 'The results that have been obtained strongly suggest that an anomaly in the formation and maturation of the synapses can have a role in the causes of autism. The identification of a melatonin deficit as a risk factor allows us to address more effectively sleep disorders in patients. Far from reducing autism to a single gene, and even less to a genetic cause alone, all of these results indicate, in contrary fashion, that the syndrome has multiple origins. Cooperation between geneticists, neurobiologists and psychiatrists is therefore more necessary than ever before to unveil the mystery of its origins' (Prof. Thomas Bourgeron, Pasteur Institute, Paris). The research, therefore, is open, in particular as regards the neurotransmitters. We can observe that most autistic individuals have nutritional and gastric problems and this can once again lead research towards the neuronal hypotheses (cf. the neurons of the enteric system[1]) without omitting other factors that interact with each other. We should note in particular that the presence of chemical products in the environment has an impact on the development of the central system.

We can never stress sufficiently, and this *is the fourth recommendation, that governments should become aware of the importance of the role that must be performed by national solidarity in financing research, providing appropriate treatment, supporting parents and envisaging initiatives when parents are no longer be alive to accompany their children who are by now adults*.

I would now like to refer to some aspects of an affective life that fosters the reawakening of an autistic child and allows him to exit from an inability to communicate, to the extent, of course, that this is possible.

2. The Reawakening of the Child in a Relationship in which he or she Feels Integrated and Reassured

Whatever may be the origins of autism, the psychological and educational approach to the situation of an autistic remains relevant. A certain approach of psychoanalysis – but not one held by all psychoanalysts – has been rebuked for blaming parents and stigmatising the mother as though she was the original cause of the disorders of her child. In general, this reality has never been demonstrated, apart from some exceptions where there is a pathogenic relationship between the mother and the child which does not lead on immediately to autistic disorders. We should not exaggerate here because a large number of psychoanalysts continue to work with parents and their children in this situation in order to help them to understand the situation, to provide them with support and to help them to engage in a relationship with their child. As one of the specialists – because we need complementariness between all the sciences – a psychoanalyst acts in an active way with the child as well in order to help him, with his capacities and singularities, to see reality and thereby establish a reassuring bond. In other terms – and we must say this again – whatever the origins of autism may be, all the approaches are necessary and are useful in facilitating the lives of these children. At times we run the risk of confining ourselves to educational measures alone, which are often very binding and run the risk of 'maltreatment' (Prof. Christian Flavigny). *That parents and specialists should work together to achieve a necessary reawakening of the child is our fourth recommendation*.

The autistic child has to be reassured when his or her basic functions are awakened, even though this involves a difficult undertaking which is at times of a complex character when it takes place within the framework of autism. And this happens in particular when the child gains access to the various stages of cognition and develops his own life of a relational character. We know that the child is invaded by sensations, emotions and perceptions which, because they cannot be filtered or integrated, trouble him because he is afraid that he will be overwhelmed by what he experiences.

'Autism is located specifically at the point where what is human in the person is awakened and it involves his various physical, sensorial, emotional and affective component parts. It expresses the difficulty and the suffering that occur when one or more components clash with each other or do not manage to order each other. Our task as medical doctors and researchers is to take into account the correlation of these factors' (Prof. Flavigny).

Through autism a child expresses the specific characteristics of the mental reawakening of children but in a way that is marked by an inability to communicate, by worry about being overwhelmed, and by the difficult differentiation between the self and the non-self which is accompanied by an absence of recognition of his own limits and the limits of other people given that given that he does not have any physical protection. Hence the importance of working upon his body.

Thus during the initial period the child experiences an 'autism', we could say, that is normal where the meeting of his needs is said to be due to its omnipotence. The neonate is in a state of primary hallucinatory disorientation. He is unable to localise the sources of his sensations, to differentiate between what comes from his body and what comes from the body of another person. He is not conscious of the maternal object, of the internal and of the external. These are primary experiences in conjunction with the reduction of tensions thanks to the relationship with his mother which helps the child to differentiate. The problem of an autistic child is that he does not manage to differentiate and to enter immediately and in a natural way into the process of individuation, which allows him engage in communication. It is difficult for him to create an intra-mental image of the mother and to employ her as a good maternal object so as to become autonomous. Separation from the self and from the object, that is to say the capacity to be himself in a suitable way in the face of someone else, like his mother, takes place with difficulty. This at times generates anxiety and violence in the autistic child.

The therapeutic and educational approach involves helping the child to gradually internalise words, names, figures, forms and colours, spaces and symbols through everything that he touches. This is a matter of creating, thanks to educational measures, an experience, not to say a neo-experience, between the child and an adult (the parents, the educator, the therapist). Thus in a gradual way the adults seek to live with him an experience between individuals starting from which he can, gradually and according to his, overcome stages that have not been completed. Work of this kind requires the adult to be in communication with his feelings in order to teach the child more effectively to take possession of them without perceiving the danger of being annihilated.

It is important for the parents not to take upon themselves and against themselves the violent attitudes of their autistic child. It is especially difficult to see their own child hit his head against a wall for a number of moments or break objects. He lacks an interior filter and is directly exposed to internal torments which he experiences physically without being able to elaborate them psychologically. As I have observed, various solutions are possible by which one can seek to reduce these forms of behaviour. Whatever the case, we must always support the parents so that they are not overwhelmed by a sense of guilt at having brought into the world a child they think is 'abnormal', otherwise we would deprive them of their readiness to perform their role as parents. When we are able to provide them with some recommendations it is surprising to observe that they also know how to adopt approaches that manage to contain the child, to act for him as a mental wrapping, to reassure him and to enable him to make progress. They experience dismay when they wonder whether these advances will last over time.

3. Undertaking and Maintaining Continuity in the Relationship

The greatest problem that presents itself to parents who have an autistic child is observing the absence of a relationship with their child or the difficulties that exist in establishing such a relationship: he is indifferent and seems to be elsewhere; he is stereotyped; social interaction is absent; and disorders are present in verbal communication. The first feelings that take hold of the parents are powerlessness at not being able to reach their child; a sense of guilt at having 'failed' with their child and of feeling extraneous to him. Very early on, they have to be helped to overcome these impressions which have nothing to do with incompetence, guilt or error. They need above all else to be reassured, informed and supported so that they gradually learn to establish a relationship with their child in order 'transplant that child into the human' and in this way that child awakes to life. One has to avoid giving them false information (data that are not confirmed) and false hopes. We must always be very attentive to all the alternative practices that they engage in inasmuch as these cannot replace the complementary therapies that are prescribed. It is true that some alternative practices (massages, good, physical game playing) can produce – although we do not know why – effects on some autistic children although not on others. In reality, everything has to work together to assure a greater wellbeing in the child and this includes attempts at socialisation and the development of basic learning in order to make it last over time.

Every child goes through a symbiotic relationship with his mother, differentiating himself a little from her. He develops the same approach with his toys which he will able to recognise at the age of four, six or eight months in order to attach himself to them, but he is not aware of the existence of an object and it characteristics. An object is a part of him and he will need time in order to realise that the object exists as such. Thus the child remains glued to an object and confuses himself with it and will encounter difficulty in being interested in two things at the same time. He cannot pay attention to the person who explains a thing to him or to the things itself – this is something that is even more difficult in an autistic child. This behaviour is evident in life at school and makes learning a complex process when the child cannot at the same time be attentive to the person of the teacher who communicate knowledge to him and to the subject of the lesson. In the face of this internal conflict, the child encounters difficulty in maintaining a feeling of continuity in time and space. His insecurity makes him aggressive and his affective relationship is broken to the point of folding in on his own body, attacking himself or attacking other people.

In this context, the relationship with an autistic child must be very interactive. Thus for example if one interests the child in an object he will not necessarily involve his own feelings or those of the person that is accompanying him. It is important at the outset for him to take possession of the object and internalise it in order to be able to use it again subsequently, starting from the name that describes it. The same takes place with an approach or a feeling which has the aim of a gradual coordination of them together.

In the case of an autistic child, an adult should have the patience to start with the primary elements that make up one by one a relationship (both emotions and sensations and the handling of objects) and thus to locate him, to the extent that this is possible, in the continuity of time by providing that child with points of reference.

4. The Strengthening of the Self of the Autistic Child

The primary organisation of the relationship within the child is pre-objectual in the sense that there is now awareness of the various objects that populate his environment and his body is seen in a fragmentary way. The first object that he perceives at a sensorial level is his mother who is an integral part of him. In an autistic child this state becomes permanent rather than primary and provisional, leaving traces in his mental life and that of his mother. Thanks to the maternal and paternal interaction, to corporeal approaches, and at times to chemotherapy, some autistic children gradually manage to have a more reassuring development of the self. The other is no longer a worry but can be recognised as different and accepted in this way for what they are.

But an autistic child can come up against two difficulties:

1. An impression of the frailty of the self can be dominant at the moment of the unification of the self. Thus objects that are broken in reality become evokers of what takes place in his intra-mental life. They translate into reality the risk of disintegration that he perceives in the frailty of his self.

2. When an autistic child imposes his own psychological situation which is moving towards a higher stage, he tends to deny all dependence on other people. The strengthening of his self passes by way of a denial of the influence of other people on him. He adopts forms of behaviour involving opposition, provocation and stupidity in order to withdraw from other people and impose his own wishes. This demand expresses a development which is painful for his parents.

Faced with these two approaches which resemble the classic process of separation and individuation, one should not react in an authoritarian way but, rather, accept them, albeit remembering their limitations and encouraging interest in various activities that begin to engage him in a way that is more or less privileged. His level of anxiety, however, must always be monitored during this period when, indeed, individuation is precarious and his self is fragile because an autistic child can become discouraged. Family, educational and therapeutic support is necessary and important in order to avoid a related mental disorganisation.

A child who does not have consistency runs the risk of experiencing other people as an irritant in his life inasmuch as he perceives them as being stronger than he is. In contrary fashion, this relationship can become a relationship of trust and he can rely upon it in order to acquire autonomy. A child can reject with violence an adult who seeks to express affection to him because he has placed in others his own aggressiveness. The frailty of his self means that he sees the other as a danger. Hence the need to develop relationships that involve trust.

Conclusion

Through this inter-subjective experience between the child, his family environment, his social and educational environment and his therapeutic relationship, a new experience is shaped starting from which he matures affectively and intellectually, learning, in the best of cases, to internalise his own sensations and perceptions that come to him from the external world. This is a complex and delicate task that places us in front of the mental suffering of an individual who is made anxious by the idea of being overwhelmed by what he feels. This is work in which the parents are involved and they should be supported within a therapeutic alliance that brings into play our capacities and suitable instruments by which to deal with the transmission of the primary aspects of what constitutes our humanity through emotions, feelings, the body, speech and the handling of objects and symbols, but also religious symbolism.

An autistic child involves feelings of extraneousness in relation to himself and ourselves. He gives the impression of belonging to another world where we do not have the means to reach him. He himself feels a sense of extraneousness towards us that brings forth essential questions about the ways in which we humanise ourselves. And yet we cannot do anything else but try to enter with him into a process of social and ecclesial integration. During the course of this international conference testimonies in this sense have been brought together which lead us to suppose that we have to live in hope and allow ourselves to be animated by hope.

Our fifth recommendation is the catechesis taught to these children which is an example of pedagogic creativity and spiritual discoveries. These children come to discover God thanks to the word of the Gospel in a relationship that connects them to Christ. The experiences of this that have been developed in the United States of America are a source of inspiration for priests and catechists who seek to develop a religious education in children and adolescents who are afflicted by the autism spectrum. One should venture with them a relationship with God in hope and not close ourselves up in clichés that seek to be inaccessible to the religious dimension and sacramental life. The positive results of this approach demonstrate this and here we could refer to various initiatives that have enriched the question. These young people have a place in the ecclesial community that they should have.

We know that autistic children do not learn in the same way and with the same ease as other children do but they can learn and know about the facts of faith, know how to live them and bear witness to them.

A discovery of the word of God and initiation into the sacraments can be offered to them through a spiritual experience that leads them to find peace and opens them to the world and to other people thanks to their relationship with Christ. The help that is provided to these autistic children should be multidimensional and this is an important thing. No approach and no educational and therapeutic activity should be excluded. Today a very large number of children have come out of their autistic bubble and gained access to communication, symbolisation and language. Catechesis has a specific role to play in this area.

Because of his special capacities, an autistic child is open to the approach of the religious dimension of existence; he is not insensitive to God. Those who attend to his Christian education must be convinced of this fact and propose pathways involving catechesis which are based upon his singular capacities, as has already by shown by numerous experiences. In this sense, the role of the word of God must be privileged because it nurtures their interiority in a calm way, opens autistic children to communication with God, and allows them to accede to symbols such as the Eucharist thanks to which they feel recognised, loved and dwelt in by God who has called them to peace. Making them enter Christian symbolism contributes to their interior unity by helping them, once again thanks to their relationship with Christ, to centre themselves once again on themselves through a discovery of the mysteries of God.

Catechesis for autistic children also allows them to become social members of the Church. They take part in the formation and the lives of Christian families. They are members here in all legitimacy and for this reason making them take part in an appropriate and suitable way in the liturgy and in the many activities of the parish should not be neglected. Care should be taken to ensure that these children (and adults), according to their needs and capacities, are not distanced from the Christian community. The catechesis that is already being taught to them is an example of pedagogic creativity and spiritual discoveries – this is a dimension that should not be neglected.

Pope Francis has invited us to go towards the 'outskirts' of existence. An autistic child belongs to these outskirts in the same way as other people who are left at the margins of society do. In his extraneousness he is a witness to the *invisible*, to everything that comes into play in the depths of human psychology and the human consciousness. At the centre of this invisibility – as is shown to us by experience – the autistic child knows how to perceive God and to ask himself about his relationship with God and his own spiritual life. He accedes to catechesis and in this sense revelation of the word of God provides him with the terms, the language and the symbolism of the gospel so that he can gradually move out of his incommunicability, 'as though he sees the invisible'.

Summary

1. The parents are not only the first educators of their child – they are also the first observers of what he experiences and they point this out to the medical doctors.

2. The role of the specialists involves supporting them in their educational role and offering various therapies and educational measures.

3. These young people who have autism are able to develop exceptional capacities and in this way they bring our aspects of our humanity that we could not perceive without them.

4. We can never emphasise enough appealing to governments so that they become aware of the importance of the role that national solidarity must play in financing research and appropriate treatment, supporting parents and envisaging initiatives when the parents are no longer alive to accompany their autistic children who have become adults.

5. The parents and the specialists contribute together to accompanying the reawakening of an autistic child in a safe way.

6. Catechesis when it is taught to these children is an example of pedagogic creativity and spiritual discoveries – this is a dimension that must not be neglected. ■

Note

[1] In December 2012 the review *The New Scientist* described certain properties of the digestive system. An independent nervous system goes from the oesophagus to the anus and connects 500 million neurons. This network that is nine metres long is called the enteric nervous system and is responsible for governing both the emotions and the digestive system!

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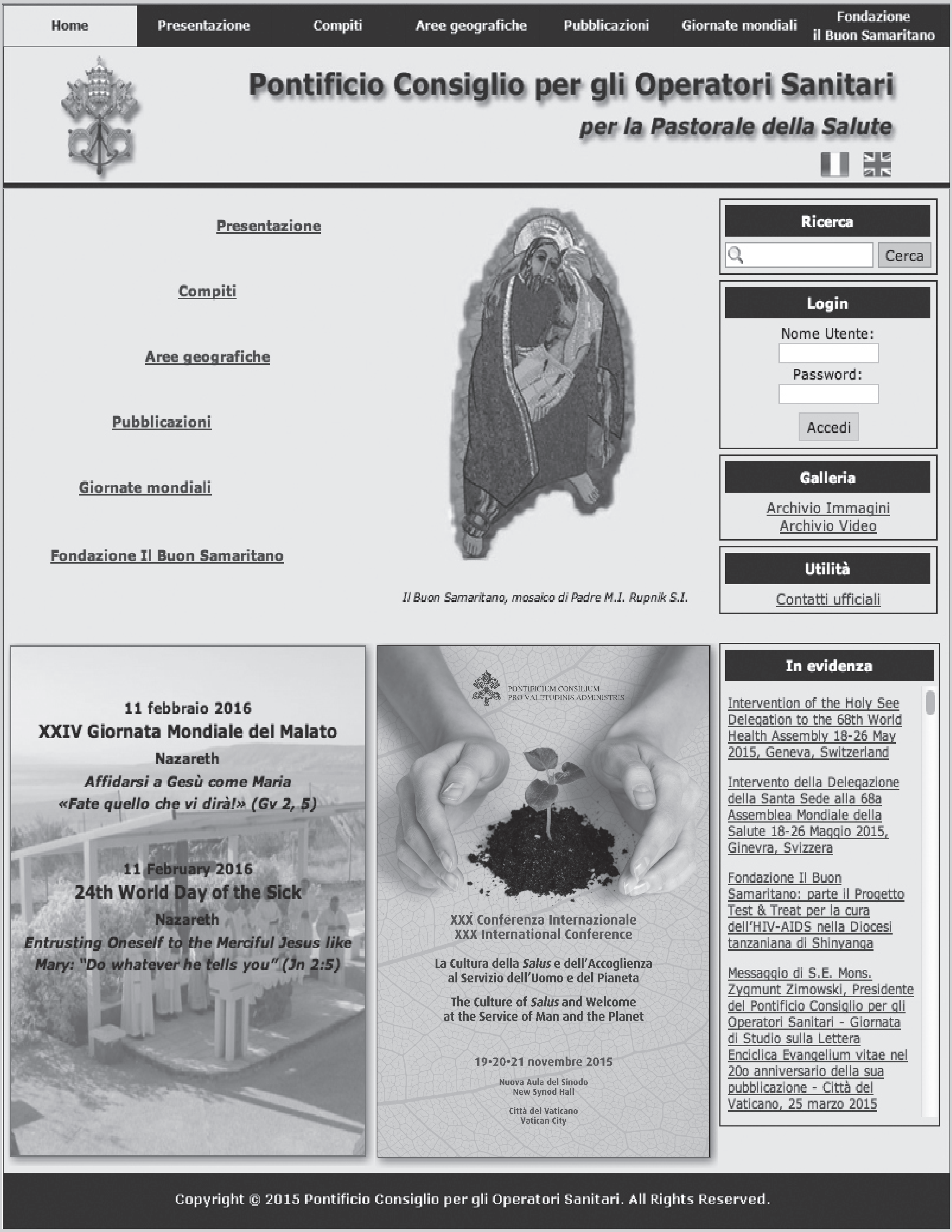

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