

# Charter of Rights for People with Autism “Reflections” and Personal Experiences

***A World Autism Organisation Publication***

*in association with*

***The Irish Society for Autism***

*compiled and edited by*

***Dr. P. Matthews & T. Matthews M.Sc.***

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## SUMMARY (Back cover)

The thoughts, ideas and personal experiences of people with Autism, parents and professionals are brought to you in this book. It gives an insight into the complexities of Autism Spectrum Disorders (condition).

It is a journey through the European Charter of Rights and a very valuable resource in creating a greater awareness of Autism and the support and understanding that our most vulnerable citizens need.

Autism Spectrum legislation is now becoming a priority in this ever changing world. We need to speed up the process so that People with Autism worldwide can benefit from diagnostic, education and lifelong support services.

I am moved by the sincerity and depth of the contributions to this book. Don't put this book on a shelf. Use it as a guide to protect and enhance the lives of people with Autism.

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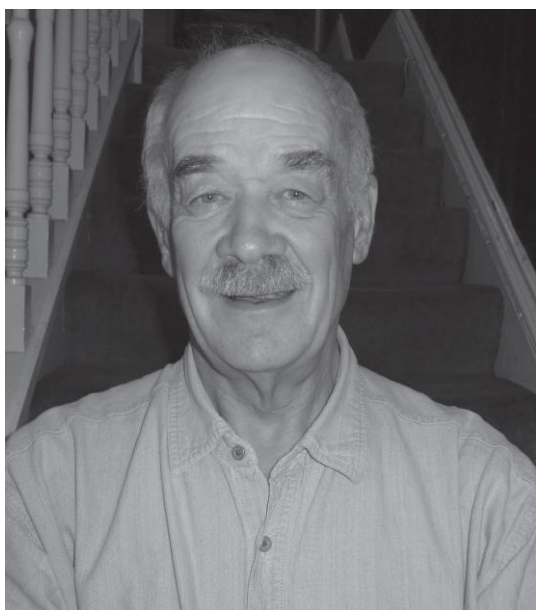
This book is dedicated to

People with Autism  
Worldwide

who in spite of their many  
difficulties have inspired  
and enriched the lives of so  
many people.

*“Together let us travel this road to a more  
caring inclusive world.”*

*Ban Ki Moon  
Secretary General of the United Nations  
2nd April 2011*



Paul Shattock O.B.E.  
*President of the  
World Autism Organisation  
and Co-Author of the  
European Charter of Rights  
for People with Autism*



Dr. P. Matthews & Mrs. N. Matthews  
*Co-Authors of the  
European Charter of Rights  
for People with Autism*

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# Foreword

## **Reflections on the European Charter of Rights for People with Autism.**

The Charter of rights for People with Autism has, since it was approved by the European Parliament in 1996, been used successfully to influence the development of autism specific legislation enacted in some countries and is a major contributor to creating a greater understanding of the complexities of Autism and the difficulties that people with Autism experience on a daily basis.

The population of people with Autism is increasing worldwide at an alarming rate from 1 in 2,000 children in the late eighties to a generally accepted rate of 1 in 100 children today. The Lancet reported in 2007 that the prevalence was 1 in 86 children and a study in the U.K. by Cambridge University Autism Research Centre indicated that 1 in 58 children will have some form of Autism Spectrum Disorder.

If we accept the validity of a prevalence of Autism of 1 in 100 children and apply it to the world population we come up with some frightening statistics.

There are 7 billion people in the world. If we accept that 1 in 100 children born will have a degree of Autism and if we fail to reverse the rise in Autism, it could affect 1% of the population of the world, 70 million people directly affected and hundreds of millions of other family members, friends also affected. This will have catastrophic consequences for communities worldwide.

# Charter of Rights

The European Parliament Written Declaration 3/96 on the Rights of People with Autism 9th May 1996 states:

The President of the Parliament announced that Written Declaration 3/96 tabled by Mrs Banotti, an Irish Member of the European Parliament, on the rights of people with autism had been signed by 331 members. Pursuant to Rule 48(4) of the European Parliament it would be sent to the institutions of the Union and the Governments and Parliaments of the Member States

## Written Declaration 3/96

The European Parliament,

- **Noting** that at least one million citizens within the EU are affected by autism, which is a mental disability, and that people with Autism can have impairments in communication, social contact and emotions, which can affect all senses including touch, smell and sight,
- **Bearing in mind** it's resolutions on the human rights of disabled people, the rights of people with mental handicap, and the Disabled Peoples Parliament; bearing in mind also the UN Declarations on the Rights of People with Mental Handicap 1971 and 1975, the European Union's third action programme on disability and the Charter for Persons with Autism,

**Calls** on the institutions of the Union of Member States to recognise and implement the rights of persons with autism;

**This declaration also points out** that people should have the same rights enjoyed by all EU citizens where such are appropriate and in the best interest of the person with autism, these rights should be enhanced and enforced by appropriate legislation in each member state and include;

- The right to live independently
- The right to representation and involvement as far as possible in decisions affecting their future;
- The right to accessible and appropriate education, housing, assistance and support services;
- The right to freedom from fear, threat and abusive treatment;

**The European Parliament instructs** the President to forward this declaration to the Institutions of the Union and the Governments and Parliaments of the Member States.

**9th May 1996**

### **United Nations**

On the 18th December 2007 the United Nations decided to designate 2nd April as World Autism Awareness day to be observed every year beginning in 2008.

This arose out of their concern “by the prevalence and high rate of autism in children in all regions of the world and the consequent development challenges to long-term health care, education , training and intervention programmes undertaken by Governments, non-governmental organisations and the private sector, as well as its tremendous impact on children, their families, communities and societies.”

The United Nations resolution also stated that “*Recalling* that early diagnosis and appropriate research and interventions are vital to the growth and development of the individual,

1. *Decides* to designate 2 April as World Autism Awareness Day, to be observed every year beginning in 2008;
2. *Invites* all member States, relevant organisations of the United Nations system and other international organizations, as well as civil society, including non-governmental organizations and the private sector , to observe World Autism Awareness Day in an appropriate manner, in order to raise public awareness of autism;
3. *Encourages* Member States to take measures to raise awareness throughout society, including at the family level, regarding children with autism;
4. *Requests* the Secretary-General to bring the present resolution to the attention of all member States and United Nations organizations.

76th plenary meeting  
18 December 2007

Each year since then the Secretary-General of the United Nations, Ban Ki Moon, has circulated a message on World Autism Awareness Day.  
Quoting from the 2011 message:

“Children and persons with autistic conditions face major challenges associated with stigma and discrimination, as well as a lack of support. Many struggle with multiple barriers in their daily lives. Far too many suffer terrible discrimination, abuse and isolation, in violation of their fundamental human rights.

Autism is a complex disorder. But in many cases the right treatment early on can bring improvements. That is why it is so important to raise awareness about the signs of autism and provide services as soon as possible.”



“Together, let us travel this road to a more caring and inclusive world.”

This year, 2012, the World Autism Organisation decided to commemorate World Autism Awareness Day by inviting 19 people, parents, professionals and people with Autism to revisit the Charter of Rights and to share their wisdom and experience with us, it is a treasure trove of thoughts and ideas that reflect on the rights, dignity and respect that are due to our most vulnerable people.

These reflections on the European Charter of Rights demand action demand the development of Autism specific legislation. It challenges all of us to examine our consciences. It demands that people with Autism be treated as people – citizens of the world who are entitled to participate in the development of Society in accordance with their individual capacity and dignity and human beings.

To repeat the words of the Secretary-General of the United Nations “ Together, let us travel this road to a more caring and inclusive world.”

My thanks to all who contributed to the success of this publication by sharing with us their personal experience and expertise.



Dr. Pat Matthews.  
*Executive Director – The Irish Society for Autism.*  
*Former President - World Autism Organisation.*

# Acknowledgement

This book was made possible by the encouragement and assistance of many people. Finding nineteen people prepared to make a contribution in less than one year was a daunting task. The constant updating, reminding contributors of deadlines, editing, collating photographs, biopics etc - the bulk of this work was enthusiastically undertaken by Tara.

I am grateful to the many contributors who gave so much of their time to make this book worthwhile.

With so many contributors in different styles proof reading and editing was a major task. Nuala Matthews and Paul Shattock gave me so much help using their expertise to guide me to the finished article.

To my friends in the Irish Society for Autism and the World Autism Organisation, thank you for your guidance and support and to Tara thank you for your patience. It was all worthwhile.

The European Charter of Rights was a project of the International Association Autism Europe which was presented at the 4<sup>th</sup> Autism Europe conference in The Hague, The Netherlands in 1992.

# 1

## **THE RIGHT of people with autism to live independent and full lives to the limit of their potential.**

This is the basic right of all human beings in a civilised society. All the other requirements which follow are means towards obtaining this substantial yet basic human right.

The consequences of being born with a disability of any sort should not include the removal, dilution or debasement of those rights enjoyed by all fellow members of society. Rather these rights and privileges should be extended and enhanced in order to ensure that the person with autism's potential is not crushed by ignorance, fear, callousness or prejudice.

# Reflections

***Hilde De Clercq***

***“The unfairness of life overwhelmed me. It was not fair to have such a child, but it was even more unfair to be that child” (Charles Hart, Without Reason)***

Rights and inclusion are issues we discuss a lot. I admit that only the fact that we have questions about these topics makes me angry and sad. Literally inclusion means “being included” and it means that people with a disability belong to society and should be able to participate in all kinds of areas like education, working, living... Who are these people that we think we have to agree upon something that is so obvious and fundamental ? Who has the right to invite somebody to join society ? (Yes, inclusion means to let somebody in, to give someone the opportunity to join) Who has the right to say it is ok for a person with a disability to belong ? How did we get included ourselves ?

It is about time that we all start to understand that we are all born with the right to join ‘the club’, that every human being is born to ‘belong’ . It is about time that the difference between being ‘autonomous’ and ‘dependent’ gets neutralized.... Inclusion is about “interdependency , interconnection and belonging”... and moreover: it should not stop when school is finished ! Being born with a disability should not mean that the rights that all other members of the community have, all of a sudden get diminished or cease to exist. People with a disability should have the right to determine as much as possible how they want to live their own lives ! Only in his way the individualized ‘quality of life’ is guaranteed.

In the ‘Charter of rights for people with autism’ we read : ‘The right of people with autism to live independent and full lives to the limit of their potential’... People with autism are said to have resistance to changes. But what about the so-called ‘normal’ people, the ‘neurotypicals’? How does society look at people who are ‘different’ and who need support ? When we talk about changes the problem is not in the person with autism but in society. Society has to change and change is a difficult process. For Ptolemaeus the earth was the centre of the universe. Copernicus changed this paradigm by putting the sun in the centre. This was a real shock... he was even prosecuted for his ideas. All of a sudden everything had to be interpreted in a different way (Covey).

In a similar way I changed my paradigm as well : looking at my child with a disability in a ‘different’ way means at the same time ‘being’ different. The way you reflect upon things, the way you see things determines and is the power, behind change. Changing from what to who, from ‘what is he?’ to ‘who is he?’

If we start from the idea that people with a disability have to be addressed as ‘citizens’ we come very easily to the conclusion that , in many cases, we have to ‘de-institutionalize’. In the so-called ‘paradigm of citizenship’ we consider the person with a disability as a co-citizen who needs support. Other paradigms show another view on people with a disability.

If we consider the concept of 'care', then we know that people with a disability in the past were put together in groups or in big institutions. These institutions were built outside town, far from the 'normal' people. People with a disability were supposed to 'enjoy' the silence and the fresh air of the countryside...They got good food, a swimming pool, all kind of therapies ('music therapy', 'horse therapy', 'occupational therapy'... and last but not least 'CARE'.

In this 'deficiency-model' (the 'medical' model) they were treated as 'patients' and they were 'condemned' to getting 'care'. This was, by the way, seen as the duty of society ! According to the 'norms' of the outside world (the so-called 'normal people') these 'patients' were having a good life and a good time : they got good care, they even got 'total care'...

Has anyone ever thought and reflected upon how these people with a disability themselves experienced this 'quality of life' ? Has anyone asked them what their dreams were for their future ? Has anyone asked their natural network how they saw the future and the dreams for these people?

In the 'developmental model' or the 'functional model' a handicap is considered as a problem in cognitive processing. The possibilities of the individual are stimulated, there are chances for development. Much is being taught and trained. There is revalidation, there are ambulant services etcetera. For adults small services are created within society. All this is very good... even though they are still inspired by the culture of the 'institution' and the 'principle of normality' . We continue to train the person with a disability so that he will be 'as normal as possible'

Looking back at my life with a son with autism (who is an adult now) I also see a paradigm-change in myself as a mother. For him to be happy I see very different things from what I thought in the past.

In the beginning, the 'diagnostic label' was very important. 'What is wrong with my child?', 'what is his label' ?

Mary Akerley who is the mother of a son with autism brilliantly explains the importance of a diagnostic label in her article 'Labels can be lifesavers'... She is right and I fully agree with her that a label gets you in the right service. If you have the label, you no longer blame yourself or your educational style and you know what kind of educational needs your child has...When I was a young mother, getting the label for my toddler with autism was priority number one...he got it and this was good... it was good at that time... in that phase of life...I didn't realize I was adhering to the deficiency model, the medical paradigm... During that period I was very occupied with the search for the right school, the right education, occupational therapy, speech therapy etc. The emphasis was put especially on items such as: is he left-or right handed? How are his motor skills? What about mathematics? Language skills? Communication? Social skills? Free time skills ? Every three months I was looking forward to reading his 'Individualized Educational Program' as each area was evaluated and progress was documented. The program was adapted, re-adapted,

emerging skills had to become passing skills...All this was very good at that time... in that phase of life... I didn't realize this was the functional, developmental model...

During that time I was really searching for everything that had to do with the 'what' of my child and the degree he deviated from 'the norm'... and especially : how I could get him as close as possible to that 'norm'...

As I have already mentioned, all this was very very good...my child got the chances to develop and he had a right to these possibilities!

Little by little I came to the conclusion that all this was very 'relative' and limited and that I had to change my point of view.

While my son grew up and especially now that he is an adult man I have more essential and deeper questions such as : Who decides upon this norm, who decides upon what is called 'the average' ? My child is a grown up and he will forever be a person with autism. I want him to be happy ! The autism ,the label, becomes less important, I do not want to focus on his limits, his disabilities, but I want to look at his possibilities and reflect upon what kind of 'support' he needs. I realize the importance of 'Quality of life'...Until now, everything has been good, very good...but nothing is good enough, if it is for your own child...

The individualized educationional program or plan has to change during the years to an 'individualized plan for life'! 'Care' becomes 'support'. He is not a patient nor a client, but 'a citizen'. He should get the chances to get experiences he likes within the society... get supported when he needs it. The most important question now is: what are his dreams in life and how can they be realized?

What does 'quality of life' mean for him ? (NOT for myself or for professionals!) What is 'a good life'? or even better : what is a good life for him ? 'WHO' is he and what does he need to reach this quality of life ? Quality of life has to do with quality of being and this is much more than quality of care !!!

'He' is not the problem, the problem is within society, because society does not have an appropriate place for everyone! The degree of your handicap depends for the biggest part upon your environment, read: upon society.(O'Neil &O'Brien)

Lots of dimensions are important in order to be happy but we seem to forget how self-evident they are for us!

According to John O'Brien five areas are threatened immediately from the moment when people get dependent upon 'care' . These areas are : relationships, choices, have a say in decisions, status and respect and last but not least.... having a place in society! Relationships: in the circuit of 'care' the possibility to have and keep a natural network and existing relationships is threatened, the possibility to meet new people gets restricted.

I worry especially for people with autism who get older and only have an exclusive relationship with one or two carers... "People can only be who they are because of the other ones with whom they live together" (Prof. G. Van Hove).

Choice and having your say in decisions : in the circuit of 'care' 'clients' loose very often the control over their own life... Other people pretend too easily that they know what is good for a certain person.

The right to choose should not at all mean that the right to get support disappears! Support has to focus on increasing quality of life !

According to O'Brien there are not enough possibilities to grow and to develop quality of life especially because too much attention goes towards the elimination of deficiencies and shortcomings.

Working on inclusion is a very slow and difficult process. There is a lot of 'resistance to changes' for the professional and also for the parent, even though they may choose for inclusion. A lot of people talk about inclusion but they do not act according to these ideas !

For the professional it is very hard because he has to give up the idea that he knows everything and that he decides what is best for the client. The professional may be frightened for things he does not understand well yet and for new responsibilities. Now the client (read : citizen) decides himself !!! The difficult issue is on one hand the fact that the client has the right to decide himself and on the other hand there is the professional's commitment. How will he react if the client does not clean up his room or drinks too much beer or smokes too many cigarettes according to the professional's criteria?

And what about the fear of losing one's job ? Moreover the new professionals have to be prepared to work together and to show respect for the most 'experienced' people ( the family and the social network of the person who needs support). Parents and professionals together will have to look at the skills, interests, wishes and dreams instead of focusing on the deficiencies...

Also for parents it is not always easy. Their position has changed over the years : in the past they had, in the same way as the 'clients', almost no voice when decisions and choices had to be made. Later on they raised their voices and were able to change many things that contributed to a better position of 'the client'. Parents became a serious partner in institutions and residences, sometimes they became clients themselves.

As parents we choose for the emancipation of our children, but this choice has consequences: our children with a disability want to be listened to and they want to have a say and an influence in their own lives. It goes without saying that this causes a lot of feelings of anxiety and insecurity in the parents. Parents are afraid that their child may live lonely, they want to continue to protect them and to act in their children's name... This is logical. These feelings are bigger, more complex, more lasting and stronger in parents of children with a disability than in parents of 'normal'

children. The talent to make the distinction between the vulnerability of your child and your own vulnerability as a parent, is not an easy one to develop. As a parent you are continuously on the balance between the danger of taking risks and the danger of over-protecting.

Change is frightening... we have to switch from a system of norms towards a system of diversity, from dependency-independency towards reciprocal dependency or interdependency: everything is interconnected.

Inclusion is not about the idea that we are all identical or that we have to become one big nice happy family. Douwe Van Houte writes about a varied society, characterized by two things:

**-equality :**

everybody has the right to be there and everybody has the right to respect. This society gives support when necessary.

**-diversity :**

people are different and these differences have to be respected. The word inclusion is very trendy nowadays. Very often I have the impression that institutions hope they will be evaluated as 'correct' if they often use the word... If we think about inclusion in a critical way we have to put ourselves in question and ask ourselves whether we really listen to people with autism and if we really make concrete changes in the life of these people according to their wishes.

It is useless to use the terminology if we do not really act according to the ideas.

'The mediocre resist change, the successful embrace it.'  
(Erik Oleson)

Good services and good professionals will always be very important. They have to find the strengths of the person with autism and try to create chances for development in society. Services and society have to change gradually. A lot of work has to be done to change existing cultural patterns, especially for people with autism who belong to a different culture. It is a difficult balance : not giving too little, not giving too much. A balance between the right to have a life of one's own and the right to get adequate and maximal support in order to live this life.

'What keeps the Person at the Centre ? The quality of listening'  
(O'Brien).



*Hilde De Clercq*



Studied at the university in Gent, Dept.of Philosophy and Literature, specialized in linguistics.

After she had her son with Autism (Thomas), she started to work in the parental society in Flanders as a trainer for parents.

In 1994 she started to work as a Parent-Professional at the Opleidingscentrum (Centre for Training on Autism, founded by Theo Peeters) and has been director of this Center for several years. She has been (co)responsible for practical and theoretical trainings in Autism in Belgium and abroad.

Wrote a book on Detailthinking ("lack of Central Coherence") in autism: 'Mum, is this a human being or an animal?' and 'Autism from within', where she explains the effects of autism thinking on every aspect of daily life (see [www.hildedeclercq.be](http://www.hildedeclercq.be)).

She is preparing a new book on "Autism, Emotions, Family life and Educational Strategies."

Is member of the International Associate Editors of "Good Autism Practice".

# 2

## **THE RIGHT of people with autism to an accessible, unbiased and accurate clinical diagnosis and assessment.**

The importance of an accurate diagnosis cannot be overemphasised. Without such a diagnosis it is unlikely that services appropriate to the particular needs of the person with autism can be provided or maintained.

The diagnosis should be based upon the criteria accepted throughout the greater part of the world as the most reliable and accurate. Although minor variations in detail are acceptable, they are currently those described in the 4th edition of the Diagnostic and Statistical Manual of the American Psychiatric Association. Any diagnostic classification must ensure the acceptance of autism as a long-term handicap rather than a result of psychological insult or temporary psychosis.

The diagnosis should be carried out by competent agencies familiar with a wide range of psychiatric disorders including autism.

The diagnosis should be performed by an agency which has no vested interest in the outcome of the diagnostic procedures.

The results of such diagnoses should be conveyed to the person afflicted where appropriate and/or their closest relatives or those responsible for their care.

(Update: Currently the 5<sup>th</sup> edition of the DSM is the accepted version!)

# Reflections

***Dr Tom Berney***

My training in psychiatry started in the mid-1970s with Issy Kolvin, a man who had distinguished autism from other psychiatric conditions. My concept of autism has been evolving steadily ever since, shaped by meeting people across a wide range of age and ability and trying to compare their characteristics with a shifting psychiatric classification. Faced with a natural condition in all its subtlety and variety, I struggled to allocate each person to their correct categorical box, in short, to diagnose, a process that, at times, seemed to take priority over describing what they were really like. Every now and again I tried to stand back and think about what it was that I was involved in: what was it that encouraged people to subject themselves and their families to a stranger's scrutiny?

## ***The meaning of diagnosis***

People wanted a label and the society they were in wanted a label. We cope with the confusion around us by labelling: give something or someone a name and it fits into the framework each of us holds in our head that allows us to understand the world and how it works. We cannot comprehend the nameless, whether it is concept, thing, force or fear.

Diagnosis is a refinement of labelling, going a step further in matching characteristics against agreed definitions. For Autism, there are the international definitions of the World Health Organisation (the International Classification of Disease) and the American Psychiatric Association (the Diagnostic and Statistical Manual); both of which are under revision to take account of the change in thinking over the last twenty years.

Defining the concept gives it a reality, especially as we discuss what we mean by a *disorder* (something that is a medical misfortune requiring treatment) as compared to a *condition* (a distinguishing characteristic that may or may not be a disability depending on the balance that is struck between the individual learning compensatory skills/strategies and society's acceptance/accommodation). The adoption of the term *Autism Spectrum Condition* in England's legislation foreshadows a wider debate as to whether the World Health Organisation should include Autism in its classification of disorder (The International Classification of Disorder: ICD) or of disability (The International Classification of Functioning, Disability and Health: ICF).

## ***What then, does diagnosis do?***

- It gives the individual an identity. It explains to them something of why they are the way they are: habits that have drawn teasing and bullying are no longer inexplicable faults, nor should they bring blame any more than should red hair or short stature. For many, their diagnosis is the introduction to a wider community, the membership of a club fostered through local services, charities and the Internet.

- It can bring absolution for the family who believed their maladroitness had caused the symptoms – although this may be coloured with regret for the way they have mismanaged them.
- It steers the clinician towards probable causes and guides the search for other symptoms that might have passed unnoticed and which, unrecognised, can remain a hidden disability.
- It gives individuals and those around them, including their clinicians and educationalists, a starting point; the formulation of a diagnostic hypothesis which becomes the basis for a plan of management. I learned to appreciate that the hypothesis was just that, no more than an hypothesis. If the plan failed in its aim of helping the individual to recognise and manage their symptoms, then the hypothesis was wrong and needed revision.
- It is the ticket to the resources and services that the person needs. For those with an intellectual disability, it should open the door to a more specific, tailored service. For those of normal ability, it may release them from generic psychiatric services for people with a mental illness or the nihilism that can come with a diagnosis of personality disorder.

In the end, a diagnosis may bring new way of seeing and managing the individual's life and be the springboard to better, more suitable services.

### ***The variability of diagnosis***

The process is a soft science for, as yet, Autism can be identified only by its psychological characteristics leaving diagnosis to be determined by a clinician's judgement. Consistency is improved by the use of agreed approaches to the way the information is gathered, by using standard instruments to define which symptoms are relevant, at what age and how clear their presence needs to be. For example, I started with the Childhood Autism Rating Scale but added the 'Handicaps Behaviours and Skills Schedule,' the 'Autism Diagnostic Interview,' the 'Autism Diagnostic Observation Schedule' and others as I responded to changing research and clinical demands. I found myself a suppliant exploring a series of sects each taught by its clear-sighted, charismatic teacher. It was disconcerting therefore to discover that, like some impressionist painting, the more closely I looked at Autism, the fuzzier it became, blurring into a wider landscape of neurodevelopmental disability. Each diagnostic interview and diagnostic instrument became a step on a journey for me as much as it was for the person I was interviewing. I work in the UK where our services all subscribe to 'care pathways,' the routes by which someone is identified, assessed and managed in a planned, coordinated fashion. It is important to have a demonstrable pathway on paper (or, even better, on a web site) whatever happens in practice. They rarely recognise the sheer variety of routes by which people achieve a diagnosis. These range from those who have diagnosed themselves on Internet rating scales, through to those whose diagnoses come from clinicians, through to those people whose autism has been sufficiently florid for them to have been engaged by a research trial. Even when it comes from a clinician, this does not mean that some standard threshold is set. Clinicians vary in their experience and perception of autism and authority and accuracy do not necessarily come together although, given the vagueness of the boundary, who is to say where autism ends and neurotypical normality begin, particularly in adulthood when

symptomatology has become less stark. In some areas there may be a reluctance to diagnose autism because the resources for its management are not available. In the early days I found some educational authorities reluctant to accept my opinion; now it is the legal system that is wary. Then there are those who, for one reason or another, fail to meet the narrow criteria for a particular research programme: on occasion, a misunderstood message has left them believing that they do not have autism simply because they were not enrolled in the research. The upshot is that the availability and threshold of diagnosis varies greatly: it is not sufficient that someone was diagnosed as having autism, it is necessary to know by whom, where and when in order to understand the extent to which the diagnosis might be unbiased and accurate.

### ***The danger of diagnosis***

Once achieved (and accepted) diagnosis provides a summary description of the difficulties which can be grasped quickly by others; it saves lengthy explanations for an unusual behaviour or need and draws attention to subtle disability. At the same time, there is the risk of acquiring a stereotype – not everyone is a savant. The risk of labels is that they encourage us to see people as members of an ill-understood group. For example, it is tempting to add ‘the,’ a mechanism which takes us to ‘the Jews,’ ‘the blacks,’ ‘the disabled’ or whatever other category we chose to see and treat a group of people as somehow less human than ourselves. Diagnosis is a particularly powerful tool medicalising the person and can bring stigma, turning the label into an epithet. This kind of diagnosis can be a bar to getting a job, a career or migration to a different country. For example, in medicine in the UK, there is an emphasis on interpersonal skills which may mean that an employer looks no further than the label of Asperger syndrome, failing to appreciate its potential strengths (such as objectivity or attention to detail) and the diversity of medical roles.

Diagnosis may therefore be dangerous so that there has to be a right to confidentiality. I have found myself spending more and more time on the preliminary questions of:

- who wants this diagnosis the individual, their parents, their solicitor or their spouse?
- and why - how will it be used? Is it simply a ticket to better services or will it pathologise the person or their problem? In one for example, an autism diagnosis may prevent parents from accepting that their unhappy child has become used to having his own way; the autism simply colours the way he expresses his distressed demands.

### ***A long-term decision***

This leads to the question as to the place for undiagnosis. While it is assumed that ADHD disappears with age and it is recognised that people can grow out of epilepsy, autism is held to be life-long. At the same time, we know that symptoms change with time and that this innate shift, combined with learned compensatory skills and strategies as well as a change in circumstances, may bring the individual to the point where the diagnosis hinders rather than helps. It is then that it emerges that, like a credit rating, the label has developed a life of its own. There is little discussion about

how a diagnosis might be removed, possibly because it is much more difficult to say that someone does not have autism than that they do.

### ***Conclusion***

Diagnosis is not uniform; it is a messy but necessary process of affirmation for in the individual and a confirmation for those around him. It is a powerful tool, which comes with side-effects and is open to misuse. However, while it must be approached with care, it should also be readily available. It also needs to move beyond simply dividing the world into those who have autism and those who do not. We need to list the developmental disabilities, such as attention deficit, executive dysfunction or incoordination, that, together with the social impairment, may be mild in themselves but can combine to produce a hermit, trapped in his home. In the end this broad, descriptive assessment is an essential step to 'seeing ourselves as others see us,' the self-knowledge needed to understand relationships with others – and therefore a right, essential to development – but only if the recipient (or their representatives) can control the process.

*Dr Tom Berney  
MB ChB DPM FRCPsych FRCPCH*



*Honorary Consultant in Developmental Psychiatry with the Northumberland, Tyne & Wear NHS Trust Associate Clinical Lecturer Newcastle University.*

*Clinical Coordinator for The Brain Bank for Autism in Oxford*

*Consultant Psychiatrist to Education and Support for People with Autism (ESPA).*

I trained as a Child Psychiatrist but then returned to the North East to specialise in the Psychiatry of Disability, working in both hospital and community. Throughout, Autism has been my research and clinical interest so that I was engaged in a regional clinic and became an ADI and ADOS trainer. I retired from the NHS to specialise in this field. I had come to know Paul Shattock well and, after some years working with the children and adolescents in a specialist school (Thornhill Park), he involved me in the development of a service for adults (ESPA).

I have also been active in the Royal College of Psychiatrists and in its development of policy and training in Autism in adults.

# 3

## **THE RIGHT of people with autism to accessible and appropriate education.**

Although some of the difficulties experienced by people with autism are shared by those with other forms of disabilities, there are particular difficulties inherent in autism which require understanding and specialised educational techniques which are not generally available in generic educational environments. Each individual person with autism should be assessed by experienced educationalists and their own particular needs determined. In order to avoid the possibility of vested interests influencing decisions this assessment should, wherever possible or appropriate, involve a substantial input from those not directly associated with service providing agencies.

A personalised package should be designed to fit the needs of the individual. This could include full integration into normal school systems possibly with special programmes. In any case, teachers should be aware of the particular needs of the individual and the family. The range of available options should include the possibility of special classes or schools for people with autism with, in situations where it is required, residential facilities. The personalised programme could well include elements providing a variety of experiences to suit the needs of the individual. In the design of any personalised plan, the use of the least restrictive environment possible should be a primary consideration.

Particular attention should be given to pre-school age children since the benefits of tuition at this stage are generally considered to be of special importance.

Parents and other family members should be partners and actively involved in the education programme since evidence suggests that such participation is particularly beneficial in autism.

The progress of each child should be constantly monitored against set criteria. Where a particular therapy is proving effective, it should be pursued; where progress is disappointing the therapy should be discontinued and replaced by other programmes. The range of possibilities should not be limited by dogmatic principles.

The provision of adequate educational facilities should not place a severe financial burden on the families involved. The situation varies between countries but in those countries where the custom is for education to be free, people with autism and their families should expect the same rights. In those countries where other systems prevail the system of payment should be no less favourable than that applied when children without disabilities are considered.



# Reflections

## ***Professor Rita Jordan PhD OBE***

### ***The Importance of Education for Individuals with autism:***

When the Charter of Rights for those with autism was written autism was already recognised as a biological and developmental disorder where education had a key role:

- in remediating the effects of the autism on development  
*and*
- providing compensatory strategies to enable a good quality of life.

Yet this recognition was far from universal and, even where it existed, there were often practical difficulties in implementing those rights to accessible and appropriate education.

### ***Varied provision of education across Europe:***

Fifteen years later understanding of autism has grown and more countries have recognized these rights to education and have policies and procedures to make them a reality. The Council of Europe held an expert committee on the education and social exclusion of people with autism across all the member countries and recorded that, in spite of great variation, all were moving forward in providing education for children with autism and in work towards social inclusion. However, the report also revealed differences in interpretation of 'appropriate' education and just what was meant by 'accessibility'.

- **Accessibility:** For education to be truly accessible and appropriate it has to be meaningful and relevant to the person with autism and barriers to full inclusion need to be removed. It is not sufficient to 'allow' children with autism to share educational facilities with their typically developing peers. Premature and insufficiently prepared and supported integration can often result in less true inclusive experiences and even in greater exclusion, as children are excluded from school or become school phobic, when faced with a hostile environment.
- **Special Education:** The atypical development in autism means that typical educational approaches are not sufficient. Education has a dual role in autism. It has the best record in improving outcomes by teaching explicitly all the things individuals with autism need to learn, which others just acquire intuitively. This 'therapeutic' role of education helps to remediate the effects of autism on development.
- **Dual Role of Education in Autism:** But people with autism also have the same rights as others to access the culturally valued skills, knowledge and understanding that form the basis of the education provided for all citizens. The issues then become how to provide the specialist 'therapeutic' aspects of

education that are uniquely needed in autism and how to provide meaningful access to the general education provided for all. Not all societies have recognized these two aspects and so policies and practices seldom provide adequately for them both.

### ***Therapeutic & Mainstream Education in Autism:***

There is confusion over the nature of the specialised therapeutic aspects of education needed in autism and a difficulty in providing access to both aspects of education.

- Clinical Approaches to 'education': Pre-school and other specialised programmes are almost exclusively devoted to this aspect, although some approaches are more 'educational' than others. In many countries, the first services to be developed for children with autism were of this kind, the goals being to address the developmental difficulties inherent in the condition. These kinds of 'clinical' programmes still sometimes constitute the specialised education that is provided for children with autism, especially when they have additional intellectual impairments.
- Inclusion: When it comes to those without any additional speech or intellectual difficulties (Asperger syndrome or High Functioning Autism) their rights to access a broad and relevant education alongside their mainstream peers is more likely to be recognised. In those cases, however, the education is almost always centred around issues of access to the mainstream curriculum and the specialist therapeutic aspects of education are either unrecognized or ignored. Since the adoption of the principle of social inclusion as a right, there has been a worldwide increase in the 'inclusion' of all children with autism in mainstream schools but there is still a long way to go to make that inclusion a reality, and not just rhetoric.

### ***The Nature of Specialist Education in Autism:***

Specialist education for those with autism is not only often confined to education as 'therapy' but is also thought of as segregated education. There is too much emphasis on the location of education and insufficient emphasis on its nature. Specialist education can take place in any setting. What is needed are:

- Knowledgeable and well-resourced staff: Staff need a range of skills and approaches, based on sound evidence-based principles, of what is likely to be helpful for individuals on the autism spectrum.
- Time for assessment: The staff also need time and resources to get to know each individual and to assess their best learning style and how the autism is expressed in this particular individual.
- A range of approaches for different goals: Research shows that there is no one approach that is better for all individuals on the autism spectrum in all situations; there are no recipes. Knowledgeable staff need to select the most appropriate approach to suit each individual (based on the individual's strengths as well as weaknesses) and to suit the goal being taught.

- A range of settings: All this good specialist teaching can occur in any setting: mainstream, generic special or specialist school, class or unit. There will be pros and cons of each different environment in each case, but 'specialist' education does not, and should not, mean segregation.

### ***The Nature of Inclusion:***

As indicated above, inclusion is a process, not a location; many children on the autism spectrum can be more isolated in mainstream schools than they would be in a separate specialist centre, if there are no positive steps to enable effective inclusion to take place. Inclusion may mean very different processes in different countries.

- Individual Support worker: In some countries, children with autism may be given a support worker to assist their inclusion in mainstream schools but, unless such persons are adequately trained in autism and in their role of assisting inclusion, such a step is likely to be counterproductive. A report in 1994 described the almost complete isolation of a child with autism in a mainstream school who was 'shielded' from contact with the teacher and the other children by the continual presence of an aide, who did enable the child to be physically present in the school, but not to understand what was going on, nor to learn how to be with others, or for others to be with him.
- All staff need training: There have been some improvements in training both teachers and support workers in autism and in their roles. However, there remain numerous cases where 'inclusion' seems to be more about containment and 'managing' a child's behaviour rather than a genuine experience of learning with others, and to be with others.
- Adapted environments: It is not to be expected that all children on the autism spectrum will be able to manage in non-adapted environments, even if specialised teaching and support is available. For some with high levels of sensory disturbance, the effects of noise, visual displays, smells, distractions, and the use of speech as the mode of instruction and control will make some schools unsuitable places in which to learn and even detrimental to their development.
- Goal is inclusion in society: However, just because a school is not suitable at present, does not mean this should be a decision for life. One goal of education for all, including those with autism, is to make individuals able to flourish within their society and, at the very least, that must mean they are able to tolerate being with others and participating in communal events, albeit avoiding some of the most severe challenges. It may be the case that some individuals on the autism spectrum will always need levels of shelter from the world, and support within it, for the rest of their lives. Yet education must help individuals increase their capacity to cope and must not accept that "benign prisons" (a description of segregated adult provision made by a parent) are all that can be achieved.

- **Steps to Inclusion:** The child may start in a small segregated setting, where everything can be tailored to the needs of that individual, but there should be a programme that moves from reversed integration (where mainstream children join the child in the special environment for some sessions) through stages into the ultimate goal of full integration. Such progression is more likely to happen where specialist and mainstream (or generic special, where appropriate) services are co-locational. This may be a specialist school sharing a site with a mainstream school, or a specialist class, unit or resource base within a mainstream school. Flexibility is required because how the child with autism can manage will fluctuate from day to day, so there needs to be a situation where it is easy to spend a morning, or even a few days in a special setting, as needed, without having to involve bureaucratic decisions on placement. This can be done by having the child be part of their ordinary class but where there is a fully staffed resource base whose task it is not just to provide a safe haven for the child who needs it but also to support and train mainstream staff and peers to help make the mainstream school more 'autism-friendly'. In the best situations, peers can be used as deliberate models and be trained to prompt the child in such useful key skills as asking for help, or telling the teacher when one has finished.

### ***Residential Schools & the 24 hour curriculum:***

There is also the issue of residential schooling and what is often referred to as the 24 hour curriculum. This latter phrase reflects the understanding that much of what children with autism need to learn concerns aspects outside of the academic curriculum, including

- communication,
- emotional and social understanding,
- the regulation of behaviour and
- daily life skills.

Clearly this learning cannot be confined to school hours and is unlikely to be effective unless it is carried out across the child's day (and night). It is well established education works best when parents are involved but the stresses on parents and siblings are severe and may become too much to manage as the child enters adolescence.

- **Support for families:** Respite care and short breaks for the family are good for enabling families to survive intact and good for the child with autism, as long as they have the same kinds of specialist expertise in care staff as are needed in specialised teaching. Sadly, such facilities are not always available to families until they reach crisis point and then it is likely to be too little, too late. That is when children are often sent to residential schools, which, however good they may be, struggle to avoid becoming mini-institutions.
- **Planned programme:** A planned programme of support for families throughout the life of the child should make residential schooling unnecessary for most children on the spectrum. As they move towards adulthood, there is increased

need for some residential provision (perhaps in short 'blocks' of time) to develop more independent skills and aid the transition to a life outside the family. Ideally, such placements should be based on educational benefits and not used because failures of support have caused a deterioration in behaviour that is beyond the scope of the family to manage.

- Support before & beyond school: Just as effective education cannot be limited to school hours, it cannot be limited to the period of life spent in schools.

### ***Pre-School:***

It is important to help parents support their young children with autism from the point of suspicion, even before diagnosis. No child will be damaged by careful and sensitive attention to how they are learning and developing and the explicit forms of communication and socialisation that are the hallmarks of a specialist autism approach. Parents need training and support and, if the child does turn out to have autism, then there is no time to waste.

### ***Post School:***

Equally, education does not, and should not, stop at the end of official schooling. Some will go on to further and higher education and will continue to need support (as will the staff in these institutions) to make these experiences effective. Vocational work will not just be about training in skills and getting job opportunities, but will involve continued education in social and emotional understanding, in how to communicate and in relationships of all kinds (friendships, collegiate, formal, sexual, and legal). Many individuals on the autism spectrum have turbulent adolescences, marred by many states of high anxiety, and are not well able to benefit from their schooling during those years. However, they may become calmer as young adults and it is important that they are given opportunities to learn and develop in their adult years to improve their mental health and quality of life. Education is vital for development and can also be fun; too many adults with autism spend empty hours that lead to depression when they could be engaged in life enhancing opportunities to learn, especially if such learning is based on their interests.

*Rita R. Jordan*

*Bsc. QTS. MSc. MA. PhD. C.Psychol. AFBPsS. OBE*



Emeritus Professor in Autism Studies: Autism Centre for Education & Research, The School of Education, The University of Birmingham, UK

After a Psychology degree, Rita taught in mainstream & special schools, including 9 years as Deputy Principal in a school for ASD. She has an MSc: Child Development an MA: Linguistics and Qualified Teacher Status. She established and ran early years provision and a toy library, for those then excluded from education, for seven years and was engaged in research on Early Intervention with families of children with severe and complex needs. She has taught special needs, language development, clinical linguistics, education, and cognitive science at the University of Hertfordshire. Her doctorate was on pronouns in autism. From 1993, she developed and ran a range of professional development programmes in autism studies at The University of Birmingham, including a web-based one. She has Chartered Psychology Status for Research and is an Associate Fellow of the British Psychological Society. She has written about and researched many aspects of autism and has been involved in training events, consultations and conferences all over the world. She established 2 journals in autism and co-edited one (Autism: the International Journal of Research & Practice) for 11 years. She has been on the editorial board of 4 journals (and remains on 3). She has served on national and international task forces and working parties to review evidence and offer advice in relation to ASD. She lectures and trains at conferences and training events nationally & internationally. From 2003 to 2006 she was the Consultant to the Expert Committee on Autism for the Council of Europe. In 2007 she was awarded an OBE for her services to special needs education. She retired from the University of Birmingham in 2007 but retains her emeritus professor status and continues to act as a consultant and trainer.

***Most recent Books***

JORDAN, R.R. (2nd edition: 2012)  
Autism with Severe Learning Difficulties  
London, Souvenir Press

POWELL, S & JORDAN, R (2n Edition: 2011)  
Autism & Learning: a guide to good practice  
London, David Fulton

# 4

## **THE RIGHT of people with autism (and their representatives) to be involved in all decisions affecting their future; the wishes of the individual must be, as far as possible, ascertained and respected,**

People with autism have a particular difficulty in making decisions. This is the result of (a) not being able to envisage the consequences of decisions which are made and (b) not being able to express their views or opinions.

Consequently, it is tempting for those having responsibility for the implementation of services to make the decisions on behalf of the person with autism and the person for whom the service is provided is left frustrated and disappointed at decisions made in his or her name. People with autism do not always make a fuss or react violently to suggestions made to them but acquiescence should not be taken as agreement with decisions taken in their name.

No effort should be spared in explaining the options available even though this may be time consuming and the explanation, perhaps, unintelligible to the subject. No attempt should be made, by the enquirer, to obtain particular responses by deception or by the omission of significant details. Exploiting the vulnerability of people with autism by allowing them to express an opinion based upon false, incomplete or inadequate information is worse than allowing no choice at all.

Even those people with the severest forms of handicap can usually make their preferences evident. Even when unable to verbalise, their behaviour, equanimity, pleasure or distaste are easily observed and their preferences determinable by those who know and understand them. When, and only when, it remains impossible to determine the wishes of individuals concerned, the person's relatives, carers, advocates and friends, (particularly those suffering from autism), may need to be consulted.

Even when the person with autism is believed to be incapable of understanding proceedings where decisions may be taken which affect them directly, they should be present during that discussion. Their physical presence will help to focus the minds on the subject of discussion and will expose and minimise comment which undermines the dignity and humanity of the individual.

It is recognised that it may not be in the best interests of the person with autism that all his/her wishes be acceded to but where such wishes, expressed or not, are overruled explanations should be provided.

All records of agreements, statements and minutes from such meetings should be subject to the approval of the person with autism and/or their representatives.

# Reflections

**Tadeusz Galkowski**

*(National Society for Autism, Warsaw School of  
Sciences and Humanities, Poland)*

For people with autism spectrum disorders (ASDs) the right to be involved in all decisions affecting their future is the most important component in transitioning from dependency to independency. For the whole of his (her) life any person with an ASD must be the single most important contributor in the many decisions and choices in managing their daily life. It is not always possible for this group of people to be able to envisage the full consequences of their wishes which inform and influence their expressed opinions. For the majority of these persons they will need our help in the management of their time, both free and structured. This will almost always remain necessary for socializing with others during early development and also for their functioning as adults.

Delayed social skills and imaginative thinking as well as limited communication abilities play important roles in achieving the levels of independence sufficient for adulthood.

Some families report that the services offered by service providers in centres for people with ASDs are neither effective nor satisfying to the client.

Long-term management and successful supportive interventions, require coordinated efforts of mental health and rehabilitation professionals who are appropriately qualified and have the essential and specific experiences in the field of ASD. The lack of recognisable physical differences in children, adolescents and adults with ASDs results in confusion so that the general public expects more than they may be able to give. The ignorance in this area is very often seen and this situation can have a substantial, negative, impact on family life.

To make decisions concerning the effective support concerning actual and future needs of the person with ASD, parents (or caregivers), should determine some priorities and consider the following questions:

1. Is the person (child or adult) able to express their views or opinion in any way?
2. Is he (or she) able to envisage the consequences of decisions which will be made?
3. Is it possible for them to express their views to parents (or other family members) concerning his/her vital needs?

The biggest mistake of all is in planning the future for the persons with ASD without any attempts to involve his/her active participation. For so many years, virtually all important decisions were made without any explanations or discussions with the persons primarily concerned or any possibility for them to influence these decisions.



All available options should be openly and fully discussed and this rule contained in this, the fourth “Right of Persons with Autism” is in my opinion *conditio si ne qua non* (“without which there is nothing”) in the treatment of this group of persons with respect, dignity and humanity.

It is necessary to inform the subject, in the most effective way possible, about all relevant options and future plans concerning vocational activities, health care, social welfare, finances and legal matters. To facilitate sufficient understanding of complicated legal matters, it can be useful to use visual aids, as well as very simple short phrases without any technical terms.

It is extremely difficult to make decisions about who will be responsible for the care to be given to people with an ASD if they are incapable of living independently. If it is, in any way, possible the person must be permitted to make the choice. It is often helpful to involve experienced representatives from Non Governmental Organisations (NGOs) to consider all available options and assist in informed decision making.

Even those parents and professionals who work with a person with an ASD, having limited functional language skills, have difficulties in obtaining unequivocal responses during decisions making discussions. In such cases it is possible to concentrate on the non-verbal responses for signals which indicate acceptance or rejection of proposals suggested by care-givers.

If the person with ASD is not capable of living independently, and cannot manage their affairs, it will probably be necessary to ensure the assistance of a support worker to help in decision making and in performing those tasks which are impossible for the person. Sometimes the role of support worker can be taken by another person who is on the autism spectrum but functions at a higher level. Such solutions would seem to be ideal but are not always possible particularly in those countries where persons with ASD who function at a higher level are not yet recognised or identified and where systems don't exist to support such arrangements.

We should ensure the availability of sufficient support structures which can promote the right of persons to participating in decision making processes and influence their future. There are three additional, mutually dependent, aspects to such initiatives.

1. **Self-advocacy** is more commonly associated with the person at the higher functioning area of the spectrum of autism and can be a key to success in the seeking of appropriate independence. Most people can find satisfaction from their lives, if they can depend on the support of others when needed. Caregivers who are engaged in advocacy must make other people aware of the needs experienced by people with Autism in their charge and explain them in a way the other people can easily understand. Self-advocacy should be taught directly at an early age. One of the best ways could be in the preparation of their own individualised education program in cooperation with the teachers.

2. **Right to disclosure** can be understood as a possibility, not an obligation. If somebody does not want to disclose any limitation, lack of certain ability, or social skills impairment, this wish should be respected. Those people who have more limited skills have fewer opportunities and more limited possibilities for obtaining employment, than those functioning at a higher level. The authorities at both central and local levels should work to assure employment, on the open market or in sheltered workshops for all persons with ASD, regardless of their functioning level.
3. **The actions of caregivers, representatives, allies** and other persons who can help in better assuring the realization of desires, wishes and preferences people with ASD, are exceptionally important. In the majority of cases the family members effectively adopt the role of representatives because they know and understand the individual needs and abilities of their relatives with ASD better than any others. Along with parents and relatives there may be a need for lawyers who can be consulted when particular problems or options must be discussed and developed.

It is recognized that in the best interests of people with ASD, their wishes and preferences can be represented by high functioning persons with autism (Asperger syndrome). Some of them have shown they can be effective as the representatives of interests of persons, who are not self-sufficient in relation to decisions affecting their future. Similar roles could, for instance, be adopted by representatives with serious motor disability, who are very familiar with social, legislative and administrative procedures involved with handicaps in general. The rights which should be available to all people with ASDs can be ignored or not sufficiently perceived as a consequence of a number of factors.

- First of all there is a total lack of knowledge and understanding about the most fundamental and vital needs experienced by this group of people in society.
- Lack of highly qualified and experienced lawyers, social workers as well as local community administration staff, adequately trained for the appropriate implementation of existing and future rights of people with ASD.
- Very weak activity of the mass media in the presentation of social, medical, psychological and anthropological knowledge concerning autism spectrum disorders. The consequences of this situation are the serious neglect and denial of rights for this group of citizen who are unable to express their own opinions and wishes.

Collective advocacy is one of the possible actions attempted together with the allies of persons with ASD. Phil Schwarz (vice-president of Asperger's Association of New England and member of Autism Network International), was for many years engaged in actions for the society of persons with ASD; firstly as an adult with Asperger syndrome and secondly as the father of a son with this same syndrome. He emphasizes strongly the importance of high self-esteem and determination in the realisation of appropriate way of actions attempted in favor of people with ASD. There should, first of all, be changes in the social environment of this group of people. Schwartz (1995). This author presents also enough important controversy related to the term of "*disability*" which is often used in many papers concerning

ASD. He describes some analogies with the situation of deaf people who refuse to allow acceptance of themselves as having the status of disabled persons. To them, this represents the “paternalism” which is manifested by the majority of hearing people toward the deaf, and imposes the image of familiar world of hearing onto the unfamiliar world of deaf people. As with people with ASDs, deaf people have serious difficulties in communication with the world of hearing and, as a result, they can also be very supportive allies for people with Autism. Very interesting and inspiring data is presented in the autobiography of Stephen Shore (2004) who presented, in his book, deep and original personal experiences of a man with Asperger syndrome, analysis of self-advocacy and effective combating for rights to make his own decisions. His CV could be the best evidence and the model for many families coping with burn-out and social isolation.

I would like to mention briefly a similar discussion developed by another author. Harlan Lane (2008) is an eminent expert in self-advocacy as practised in the milieu of deaf people. They reject the imposition of the disability label upon themselves as it risks encouraging wrong solutions. Deaf persons in many countries (including Poland,) prefer be treated as a group such as an ethnic minority which has its own linguistic characteristics, its own history, culture and identity. In this light this group of persons should enjoy the rights and protections the same as other ethnic minorities under international law and treaties (United Nations, 1992).

It seems reasonable to emphasise the right of people with ASD to decision making with the partnership and cooperation of their representatives (if is necessary) in a way which will reinforce their identity and cultural and creative activity. The allies from other minorities can help people with ASD to overcome the obstacles in social integration and will permit them to reinforce their feeling of identity. I would like to mention the very simple and exceptionally substantial right of people with ASD, a right emphasized in one paper by Pat Matthews (2009), which expressed all others postulates and requirements: “People with Autism must be treated with respect and dignity. They have the right to grow and develop as unique individuals”.

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Resolution 47/1135.New York, N.Y.: United Nations.

## Tadeusz Galkowski



Born April 6, 1936 in Czeszochowa, Poland, where he attended a state secondary school. In 1957 he obtained an MA degree in psychology at the Catholic University in Lublin. He was awarded his doctoral degree in 1967 in Cracow (Jagiellonian University), after presentation of his thesis about psychological care for young deaf children. In 1956 T. Galkowski was appointed to the outpatient clinic for patients with speech and hearing disorders in Lublin, and in 1958 was installed in Warsaw, where he worked in the Warsaw School of Medicine, Center of Phoniatrics in Clinic of Otolaryngology. In 1983 he obtained the post of full Professor at the Faculty of Psychology, Warsaw University. Actually is employed in the Chair of Neurorehabilitation, Warsaw School of Social Sciences and Humanities.

Significant publications by Galkowski in this period included papers issued in international journals (*Folia Phoniatrica*, *Acta Paedopsychiatrica*, *Psychotherapy and Psychosomatics*, *Acta Medica Polona*, *Developmental Medicine and Child Neurology*). In the period 1966 – 1995, during his scientific stays in France (where was engaged in different research programs and employed by National Institute of Health and Medical Research – INSERM), he acquired experience and had numerous contacts with French professionals engaged in the study of ASD. In 1990 T. Galkowski with his coworkers created in Poland the National Society for Autism and is up to date the president of this nongovernment organization.

This society was previously included as a separate branch of another non-profit organization-“Polish Society for Handicapped People”. He is since 1986 the editor-in chief of the biannual journal “The Autistic Child. In 1996 during General Assembly of international association Autism-Europe in Luxemburg, he was one of the national representatives, who were founders of The World Organization of Autism.

He is author or coauthor of books, articles and other publications about autism and is very well known as the one of the international experts in this field. In 1981 he created in Warsaw - first in Poland – a school class for children with ASD, which functions up to date. T. Galkowski is known also as the initiator of different forms of motor, cognitive and early intervention approaches destined for people with ASD. Many MA and PhD. thesis related to ASD were prepared under his direction. As the president of National Society for Autism in Poland he coordinated many research and demonstration projects realized in cooperation with British, Irish, French and American professionals. In 1977 he was awarded by J. Chirac the Silver Medal of Paris, for his achievements in the area of supporting rehabilitation of children with developmental disorders.

# 5

## **THE RIGHT of people with autism to accessible and suitable housing.**

Satisfactory housing is a basic requirement for any form of civilised life. The person with autism will be unable to obtain housing or to pay an economic rate for it without the support of others. Such help as is required should be available from the public authorities.

The type of housing provided should be commensurate with the needs, abilities and, as far as possible, the wishes of the individual concerned. It should not be remote and isolated from society but should, as far as practicable, be in an area where support from family and friends is possible.

The type of housing should correspond, in quality, with that available to the rest of the population. Multiple occupancy of bedrooms or a ward structure where toilet and personal hygiene facilities are shared by many would not be considered suitable housing.

All forms of housing should be the least restrictive possible given the needs and the safety of the individuals concerned.

# Reflections

***Ros Blackburn***

## ***Several issues arise in this section:***

- Heterogeneity: The key word to this section of the charter is 'suitable'. It seems to me that the difficulty here is that Autism Spectrum Disorder (ASD) includes such wide ranging issues. I tend to think of it as an arc, with Asperger Syndrome at one end and pure Kanner Autism at the other and every possible variation in between.
- Involving all stakeholders: To find housing suitable for each individual with ASD is an admirable objective but its achievement requires an enormous amount of imagination, understanding, flexibility and co-operation on the part of parents, carers, governments, housing authorities, care home owners and managers, all in collaboration with the individual concerned.
- Supporting, not 'taking over': People with ASD have a wide range, and often bizarre combination of, abilities and disabilities, and care providers seem to find it extremely difficult to 'fill in the gaps' -in other words help where help is actually needed - and not to take over the whole life (or 'package' as they like to call it) of the disabled person.
- A personal example: Taking myself for example, I am intellectually fairly able and have good speech but I am also severely autistic and therefore cannot cope with people. I am extremely fortunate in that I have privately-owned, self contained accommodation. Because my parents were creative, caring and determined to make me as independent as possible, I have been taught to observe (even without understanding) most of the social conventions, and have learned by repeated instruction and demonstration how to keep my home and myself clean and relatively tidy, But I have only very basic cooking skills and decision making is still a nightmare. Because I can contact my parents on the telephone at any hour of the day and night I can cope more or less. But they are almost 80 and what happens when they are no longer around?

## ***So what are the options for a person with ASD?***

1. **Entirely independent living in self contained accommodation:**  
Even with the most intellectually able and high functioning person with ASD there are going to be times when support will be needed. This can be at any time of the day or night! While at times an empathic voice at the end of a telephone may be sufficient to solve the problem, it is not going to stem a flood in a flat. In my case it is not inside my home that I encounter the worst problems – it is when I need to go out. To achieve this I need hands on human support everywhere I go. I am only able to earn my living because my carer is there with me all the time. I do not need her there to help me do the

job itself but to cope with the unexpected, and in particular with the curious things that non autistic people say and do.

2. **Sheltered housing with on site support:** In this option several people with ASD are housed in individual self-contained units each having its own living, sleeping, cooking and bathroom facilities. 24 hour help is available on request by a 'warden' living on site. This is an ideal option for the more able.
3. **'Independent' living with support:** In this option the person with ASD lives alone but with support provided for a specific time and purpose, for example help with cooking, cleaning, personal care etc. For this to work well the person with ASD must be relatively able and there must be sensitive communication between the helper and the individual.
4. **So called 'Independent' living with 24 hour care:** In this option the person with ASD is far from independent and in the worst scenario their life and home can be completely controlled or taken over by the carer. In my opinion this sort of accommodation is not suitable for the more severely intellectually and functionally disabled person with ASD.
5. **Shared housing with 24 hour care:** In this option 2-8 people with ASD are accommodated in a house with two or more carers on duty at any time. Each person has his or her own bedroom often with en-suite facilities. There is a communal sitting room and kitchen. With only two or three 'clients' this is not only an expensive option but may also cause difficulties for the people concerned if they don't get on. With a larger number of residents there is greater opportunity for the individuals to choose whether or not they socialise, and with whom, and this may be particularly to the liking of those with Kanner autism.

#### ***Problems with Options 1-5:***

- In options 4 and 5 any resemblance to normal home living is often completely obliterated by over rigorous health and safety observation. Quite often what should be a cosy home becomes a mini institution
  - Much emphasis is placed on 'Care in the Community' but for many people with ASD this is a myth. As a result of fear, ignorance, or indifference, a large proportion of the community does not care. Locating people with ASD in the community in the hope that they will blend in is futile. Location is not synonymous with inclusion.
  - With options 1, 2 and 3 an added problem is that the person with ASD can become isolated from society. With options 4 and 5 this is less likely to happen but they may have little contact with their peers.
6. **Large group home:** In this option any number of people with ASD may be housed in a single community. The accommodation can range from a single large building, where the residents have their own bedrooms but share other

facilities, to a variety of other structures, which may include flats, chalets and single occupancy accommodation within the grounds. While, in this option, the accommodation itself is often of a very high standard; life for the occupants can vary considerably. Some of the better ones are those where the residents are encouraged by paid or voluntary labour to help support their community. In one such community that I have visited, some of the people with ASD can work in the shop, while others do woodwork, help in the café or work on the community's farm, tending animals or growing crops. This option can cater for all levels of disability but it does require high level of support and is therefore expensive. However, this is time and money well spent in that the residents acquire a sense of purpose and self worth.

### ***Policy & Practice***

*The Benefits System:* In the UK, as in other countries, the big disadvantage for people with ASD is that unless they are living in privately owned accommodation, they are dependent on the housing benefit system and are greatly disadvantaged in, if not totally discouraged from, finding employment.

*Continual Scrutiny:* People with ASD and high support needs are the most scrutinized of any human beings and the big problem in care homes is to balance watchfulness with lack of intrusion. I once had occasion to spend the night in a respite care home for adults with disability. The accommodation was excellent and the carers were kind and pleasant. However, I was watched over, interfered with and checked up on to such an extent that I finally lost control. Carers need to care more with their eyes and ears and less with their hands and voices.

*Quality of Life:* Another misconception regarding any person with a disability, including those with ASD, is that they must be constantly entertained, have everything they want and never need to do any work. In my opinion this does not equate to 'Quality of Life' and bears no resemblance at all to real life.

LOGICALLY ILLOGICAL  
Information and insight into autism



## *Ros Blackburn*



Ros Blackburn is an adult with autism. At three months old she appeared withdrawn, isolated and very much in a world of her own. At eighteen months she was diagnosed very severely autistic but with average intellectual ability. Now at 42 Ros lectures nationally and internationally giving insight into her own experiences and the care and education practices she has observed. In spite of the severe limitations imposed by her condition, Ros displays great courage (and a strong sense of humour) in facing her fears and tackling life's challenges.

Ros draws on her experience of living with severe autism and her considerable experience both as a recipient of services and increasingly as an observer of education and care approaches. Ros brings a perspective that is unique and yet speaks to all her audience: people with an autism spectrum disorder, carers, families, educators and the planners and providers of these services. Ros tells it 'as it is'. She does not disguise the fear and limitations which are part of her daily experience. Yet she is also able to convey her wonderful capacity for fun and zest for life and her refusal to accept 'second best' for herself or for others. She describes the approach taken by her parents to give her what she now describes as the 'veneer of social competence' that enables her to engage in a still largely autism-unfriendly world. She explores with humour and passion the 'mistakes' from which she has had to learn and some of her coping strategies. From these she is able to offer helpful advice on practical strategies (and even more helpful advice on what not to do!) Her talk also illustrates the problems of having an uneven profile of strengths and weaknesses, where often the strengths mask her very real difficulties and needs. She does not advocate any one approach except that we should remember that people with ASD are people too and that 'common sense' should apply. Her position can best be summarised as an insistence on the need for high expectations for people with ASD linked with equally high levels of support. In a quote from her mother, Ros pleads that one should 'never make autism the excuse, but help the person overcome the problems caused by it'.

Finally, it is Ros' wish that all those who attend her talks find them helpful and informative but above all that the experience is entertaining and full of fun.

# 6

## **THE RIGHT of people with autism to the equipment, assistance and support services necessary to live a fully productive life with dignity and independence.**

The provision of appropriate housing is but the first requisite in the creation of a satisfactory environment for people with autism. The facilities within the home should satisfy the same regulatory and safety standards as are required in normal housing. In any group situation, the facilities should permit withdrawal from other members of the group when requested by the individual. Furniture, furnishings, equipment and consumables should be 'non-institutional' in design and should encourage the expression of individual preferences and interests.

People with autism should be encouraged to take a proper pride in their appearance. Clothing should be of the type and quality available to the normal population. The provision of old, second-hand, old-fashioned or uniform clothing is degrading and stigmatising to the individual. Parents and carers must be conscious of the possibility of enforcing their own standards of dress upon children with autism when such styles would attract attention in much younger children. The same considerations would apply in other areas such as hairstyles, make-up or ornamentation.

People with autism will always need a degree of continuous support. In some cases this support may need to be only at 'arms length' where the mere knowledge that support is available is sufficient encouragement for the person with autism. For the vast majority considerable support will be required and should be available at an appropriate level. Such support should not take the form of merely caring for the individual by feeding, cleaning and assuming responsibility for all decisions. The support should be designed to encourage independence in the individual by helping him or her to take responsibility in these areas.

Although it is not always evident, people with autism do take pride in their appearance, their achievements, skills and independence. Developments in all these areas lead to an increase in the confidence and dignity of each person.

# Reflections

## *Temple Grandin*

### ***Requirements For Success***

Autism is a very broad spectrum and the type of supports that are needed will vary. The one thing that everybody can agree on is that very young children with autism need 20 to 30 hours a week of intensive teaching. The worst thing that one can do with a 2- to 3-year-old child with autism is to let him/her watch TV all day. Young children with autism need to be kept engaged by an effective teacher. Teaching should start when symptoms are first observed. Early educational interventions can help reduce the need for expensive support when the child is older. The research is very clear intensive educational programs started when symptoms first appear are effective.

The severity of autism can vary from a mild case of Asperger's syndrome to a person who remains non-verbal and has other severe medical problems along with autism. Some individuals who remain non-verbal can learn to type. Tablet computers such as the Apple iPad have Apps that can convert a tablet into an economical communication device. Everybody has the right to be able to communicate. For individuals on the milder end of the spectrum, social skills training and learning basic skills is essential. When I was a child, I was taught to be polite.

Mentors are needed to help individuals with high functioning autism and Asperger's to develop skills and succeed in both school and employment. My science teacher was an essential mentor who got me motivated to study. Employers need to be trained to effectively work with individuals on the autism spectrum. They need to give autistic employees clear directions on the task at work. When a social mistake is made, the boss needs to clearly explain what was done wrong. Being subtle does not work. The person on the spectrum needs to be quietly coached on the correct behavior.

## *Dr. Temple Grandin*



Dr. Temple Grandin was born in Boston, Massachusetts. Temple's achievements are remarkable because she was an autistic child. At age two she had no speech and all the signs of severe autism. Fortunately, her mother defied the advice of the doctors and kept her out of an institution. Many hours of speech therapy, and intensive teaching enabled Temple to learn speech. As a teenager, life was hard with constant teasing. Mentoring by her high school science teacher and her aunt on her ranch in Arizona motivated Temple to study and pursue a career as a scientist and livestock equipment designer.

Dr. Temple Grandin obtained her B.A. at Franklin Pierce College in 1970. In 1974 she was employed as Livestock Editor for the Arizona Farmer Ranchman and also worked for Corral Industries on equipment design. In 1975 she earned her M.S. in Animal Science at Arizona State University for her work on the behavior of cattle in different squeeze chutes. Dr. Grandin was awarded her Ph.D in Animal Science from the University of Illinois in 1989 and is currently a Professor at Colorado State University.

She has done extensive work on the design of handling facilities. Half the cattle in the U.S. and Canada are handled in equipment she has designed for meat plants. Other professional activities include developing animal welfare guidelines for the meat industry and consulting with McDonalds, Wendy's International, Burger King, and other companies on animal welfare.

Following her Ph.D. research on the effect of environmental enrichment on the behavior of pigs, she has published several hundred industry publications, book chapters and technical papers on animal handling plus 45 refereed journal articles in addition to seven books. She currently is a professor of animal sciences at Colorado State University where she continues her research while teaching courses on livestock handling and facility design. Her book, *Animals in Translation* was a New York Times best seller and her book *Livestock Handling and Transport*, now has a third edition which was published in 2007. Other popular books authored by Dr. Grandin are *Thinking in Pictures*, *Emergence Labeled Autistic*, *Animals Make us Human*, *Improving Animal Welfare: A Practical Approach*, and *The Way I See It*.

Dr. Grandin has received numerous awards including the Meritorious Achievement Award from the Livestock Conservation Institute, named a Distinguished Alumni at Franklin Pierce College and received an honorary doctorate from McGill University, University of Illinois, and Duke University. She has also won prestigious industry awards including the Richard L. Knowlton Award from Meat Marketing and Technology Magazine and the Industry Advancement Award from the American Meat Institute and the Beef Top 40 industry leaders and the Lifetime Achievement Award from The National Cattlemen's Beef Association. Her work has also been recognized by humane groups and she received several awards.

HBO has recently premiered a movie about Temple's early life and career with the livestock industry. The movie received seven Emmy awards, a Golden Globe, and a Peabody Award. In 2011, Temple was inducted into the Cowgirl Hall of Fame. Dr. Grandin is a past member of the board of directors of the Autism Society of America. She lectures to parents and teachers throughout the U.S. on her experiences with autism. Articles and interviews have appeared in the *New York Times*, *People*, *Time*, National Public Radio, 20/20, The View, and the BBC. She was also honored in Time Magazines 2010 "The 100 Most Influential People in the World." Dr. Grandin now resides in Fort Collins, Colorado.

# 7

## **THE RIGHT of people with autism to an income or wage sufficient to provide adequate food, clothing, accommodation and the necessities of life.**

If the dignity of the individual is to be conserved, the money required to purchase appropriate provisions or support the personalised plan should be sufficient. It should be allocated to the person so that if alternative placement is found the money to support it is available. Wherever this is feasible, it should be paid in the form of a wage or salary to be used for the purposes described above. Even where the support is directly attributable to a work programme but is in the form of a grant, it should still continue to go with the individual. The burden of payment for service provision should be the ultimate responsibility of the community at large and should not rest entirely with the family of the person with autism. This does not, of course, preclude the provision of additional items or services by the family.

A financial allowance of some sort should come under the direct control of the person with autism. The person should be completely free to spend this allowance on whatever he or she chooses provided that the chosen items are not harmful to the individual or to others.

# Reflections

***Professor Tony Attwood,  
Brisbane, Australia***

People with autism should have the same rights as ordinary citizens. However, the nature of autism, and the effects on the individual, necessitates special consideration, especially with regard to food, clothing, accommodation and necessities.

## ***Food***

One of the characteristics of autism, now recognised in the new DSM V diagnostic criteria, is a hyper sensitivity to specific sensory experiences. Food has many sensory dimensions including taste, temperature, liquidity, colour, aroma and texture. People who have autism frequently have an aversive sensory reaction to certain foods such that special consideration is needed with regard to the range of food that can be tolerated. Carers and clinicians recognise the aversive and phobic reaction of people who have autism to certain types of food. We currently do not have therapy programmes to successfully eliminate sensory sensitivity to food.

In addition, we recognise that autism can be associated with auto-immune disorders such as coeliac disease and food intolerance and toxicity. Clinicians and dieticians often support care givers of people with autism in acknowledging the need for a diet that avoids certain foods that, for example, contain gluten or wheat.

Thus a restricted range of food tolerance associated with autism means that the person's income must be sufficient to accommodate food sensitivity and a restricted diet.

## ***Clothing***

The sensory profile of people who have autism also includes tactile sensitivity. This has an effect on the range of fabrics that can be tolerated in clothing. Often items need to be washed many times before the tactile sensation of wearing the item is reduced to a tolerated level. Some fabrics have to be avoided altogether. Thus the person with autism will need an income that can include the purchase of clothing that is within the person's range of sensory tolerance which is usually for natural soft fibres.

## ***Accommodation***

Perhaps the central characteristic of autism is a qualitative impairment in reciprocal interaction. Social interaction skills can be learned, but socializing can lead to exhaustion, as success is achieved by intellectual analysis rather than intuition. Having too many people in close proximity and being required to socialize beyond a limited capacity for socialization invariably leads to agitation and a desperate need to recover emotionally through solitude. Thus accommodation for someone with autism needs to include sufficient personal space and opportunities for periods within the

day of privacy. The need to have sufficient personal space also applies to the area around the building, with freedom to walk in a safe area.

The home of the person with autism is also a sanctuary that should allow tranquillity as well as solitude. Thus accommodation will require greater personal space than would be considered for a typical adult. Thus the costs of accommodation are likely to be greater.

### ***Necessities***

There is recognition of the basic necessities of life but people with autism have additional necessities. One of the characteristics of autism is having a special interest, usually the collection of objects and information. Caregivers and clinicians recognize that one of the greatest pleasures in life for the person with autism, often greater than interpersonal pleasures, is spending time engaged in the special interest. The interest has many constructive functions, from intellectual enjoyment to being a 'thought blocker' to act as a barrier to feelings of anxiety or sensory and social overload. Thus the person's income needs to be sufficient to engage in a special interest.



*Professor Tony Attwood*



Tony is a clinical psychologist who has specialised in autism spectrum disorders since he qualified as a clinical psychologist in England in 1975. He works in private practice in Brisbane, but is also adjunct professor at Griffith University, Queensland. His book *Asperger's Syndrome – A Guide for Parents and Professionals* has sold over 350,000 copies and has been translated into over twenty languages. He has worked with over 6,000 individuals of all ages with Asperger's syndrome or an Autism Spectrum Disorder.

Tony presents workshops and runs training courses for parents, professionals and individuals with Asperger's syndrome all over the world and is a prolific author of scientific papers and books on the subject. His latest book *The Complete Guide to Asperger's Syndrome* was published in October 2006.

# 8

## **THE RIGHT of people with autism to participate, as far as possible, in the development and management of services provided for their well-being.**

The person with autism must be encouraged to participate in all decision making processes which concern services provided for their benefit. The denial of such rights is illogical and unnecessary and appropriate mechanisms must be found in the design and implementation of all such services.

In a group situation such as a group home or small community, all people with autism should be consulted and given the opportunity to be included in any decision making process which affects the operation of the service.

Autism presents special difficulties which may preclude the appointment, by the members of the group, of a representative who can speak on behalf of all. The involvement of each individual is, therefore, important. The service users should be involved in decisions about all activities especially those connected with leisure time, food, furnishings, decorations, rules, timetabling, outings, entertainment, work experience, future plans and developments.

Even when the person with autism apparently contributes little to the final decision, their presence and potential for involvement will limit patronising behaviour and will enhance the confidence and self esteem of that individual.

# Reflections

**Theo Peeters**

***“No , no, I disagree completely: people with autism should not have the right to participate in the development and management of services provided for their well-being...”***

I imagine your blood pressure rising, your body beginning to tremble, your fists clenching and your brain trying to get your mouth working, thinking ‘What an idiot to say something so stupid ... This person doesn’t seem to know the first thing about autism ...

Yet, as I cannot see any reasonable argument to deny this right (as formulated above) , I’ll focus on the misunderstandings and confusion about autism and Asperger’s syndrome that may be at the origin of such a silly and unethical denial ...

The quote above (from a hypothetical ‘enemy’) reflects extreme stupidity, but we have seen that in both the past and the present other excuses for ‘resistance’ have been formulated, most of the time based on misunderstandings, a mistaken idea of what autism really is.

First of all there are still many people who look at autism from the outside, focusing on behaviour, instead of what the behaviour reflects, thus, from the inside. ‘If Leo Kanner and Hans Asperger had been anthropologists ...’ the history of autism might have been very different. The ‘traditional’ psychologists (in many countries and continents, not in all, the situation has changed) tended to interpret autism according to what they saw as “normal” so autism was seen as a psychopathological phenomenon, a ‘disease’, a mental illness. It was only when it became more and more clear that autism had a biological origin and that people with autism had a brain that treated information differently and had many conceptual difficulties, that the educational approach became the treatment of choice. Autism is seen now as a spectrum: it can go together with learning disabilities or with higher levels of intelligence (sometimes called Asperger’s syndrome , ‘the most invisible of the invisible handicaps’). Yet, many so-called normal people are afraid of what they do not understand, and so have a tendency to reject ‘neurodiversity’, instead of welcoming it.

In the past autism was often associated with a symptom (being aloof, self-absorbed). Often, though not always, people who are aloof also have a profound to severe learning disability. Yet, nowadays, this symptom is not necessary for a diagnosis of autism, indeed most of the time it is not present.

Recently (since Lorna Wing’s and Utah Frith’s re-discovery of Hans Asperger’s writings) we have been presented with ‘non-biased autism’ , that is, autism without co-morbidity. We understand now better than ever that many (not all) mental problems (depression, anxiety psychosis, obsessive compulsive problems, selective mutism a.o.) are not necessarily part of autism itself, but are secondary problems,

caused by frustrations when confronted with a society where there is little understanding of autism. So non-biased autism is not a medical problem. If people talk about a 'cure' it is only a cure of these secondary problems. The different ways of dealing with such a state of mind is not to try to cure it---it is innate and forms an essential part of autism --- just as we cannot be 'cured' from our neurotypical conceptual development.

The concept of autism has developed as meaning, first, a symptom (e.g.aloof), then a syndrome (the triad of social communication, social understanding, social imagination)(Lorna Wing) and then further as a spectrum, the autism spectrum.

Many people do not seem to realize that along with an autism spectrum, we also have a neurotypical/or 'normal' spectrum.

A U T I S M Spectrum  
*Learning disability >> Higher IQ's(AS)*

N O R M A L Spectrum  
*Learning disability >> Higher IQ*

You see that in both spectrums there are high IQ's (high intelligence) and low IQ's

- Why do we understand 'typical development' in combination with a learning disability, better than
- Autism in combination with a learning disability?
- Because in the 'normal'(NT) spectrum a learning disability has to do with the same type of intelligence, the same type of brain function(treatment of information) that we are used to.
- In the autism spectrum it is a learning disability in combination with a different type of intelligence, a different type of brain function (treatment of information)
- There are also different types of learning disabilities: profound,severe, moderate, mild ...
- We also have different types of neurotypical development: profound, severe, moderate and mild.

You could almost say that there are people who are 'severely normal', i.e. the neurotypical people who have very strict criteria about 'normality' who usually feel that they are superior to those who are 'different', and want to deny that people with autism are citizens just like them with the same rights.

It seems like many people in our culture suffer from a cultural superiority complex, as if we set the standard for happiness, that our quality of life should be accepted by everyone, no matter how different. Some may find the next comparison exaggerated, but is it? What has our 'white European' culture got to do with Africans, North and South American Indians, the Australian aboriginals.... Trying to understand these cultures from within certainly has not been their priority....No more than understanding people with autism from within has been our cultural priority

either...But why not? 'Because they are different, sir, and we are not going to make an exception for that very reason'.

No exceptions, not even when trying to develop an 'inclusive education (to create an inclusive society)', no exceptions!

Now we come to the difference between 'equality' and 'equity'. Equality is not always 'democratic': if you earn 1000 € a month and for a parking ticket you have to pay the same amount as someone who earns 10.000 € a month, equal, yes, but that is not social justice ...

If your development has been different (eg a pervasive developmental *disorder* for those who have a combination, a pervasive developmental *condition* for those who manage to integrate into our society) ... but they merely give you 'equal rights', that is not very ethical either. People with autism need something else: equity, in the form of different rights as compensation for their particular differences ...

Inspired by a Bhutan fable (shown to me by Jannick Beyer when he worked for Unesco in Bhutan), I developed the following little story to illustrate this.

'Once upon a time there was a teacher who believed in the principle of equal rights for all of his students---a giraffe, a mouse, a frog, a dog, and a bird. One day he told them what he meant by 'equal rights'. ... He said to them : 'I want to treat you all the same, with no differences. Now, high in that tree there is a treasure and you'll recognize it quickly because of its red colour. The one who gets it first and gives it to me, is the winner ...'.

I'm sure the ignoramus whom I introduced to you at the beginning will think that teacher had a fine idea. No exceptions, the same rules for everyone ... !

Compare this to a few quotes from some very high functioning people with autism. How do they see the coming together of the two cultures...?. Jim Sinclair (a well known person with autism) talks about building bridges between the two cultures, the autistic one and the neurotypical one : '... *Recognize that we are equally alien to each other, that my ways of being are not merely damaged versions of yours. Question your assumptions. Define your terms. Work with me to build bridges between us*'.

And Gunilla Gerland, a Swedish woman with autism: '*I have this picture of two cultures (the autistic and the NT ) as two gardens with a fence between them. Some people may be able to walk up to the fence and speak to people from the other culture, while others are very far away from the fence. I often find myself sitting on the fence, sometimes there is someone sitting there along with me, but this is rare: there's lots of space on the fence. More and more people from both cultures are walking up towards the fence to speak to each other though and I think that is great*'.

And so, do people with autism have the right **TO PARTICIPATE, AS FAR AS POSSIBLE, IN THE DEVELOPMENT AND MANAGEMENT OF SERVICES PROVIDED FOR THEIR WELL-BEING, YES, ABSOLUTELY YES ....**

*Theo Peeters*  
([www.theopeeters.be](http://www.theopeeters.be))



Licentiate in Philosophy and Literature, Univ.Louvain  
Master in Neurolinguistics,Univ.Brussels  
Master in Human Communication, Univ.London  
Psychoeducational approach autism .TEACCH,Univ.of North Carolina,USA  
Has founded the Opleidingscentrum Autisme (Center for Training in Autism in 1981)  
Was asked by the Ministry of Education to give training to teachers and para-medical staff for the first official 'Experiment in Autism in Special Education' (1985).  
Has been responsible with his colleagues for training in autism in most of the countries in Europe but also outside Europe (Chile, Peru,Colombia, Mexico, Argentina a.o.).  
Has published many articles and 6 books on autism in Dutch. Several have been translated into many different languages. The special focus of the Opleidingscentrum is on 'understanding autism from within', therefore emphasizing meaning and trying to understand autism through the eyes of persons with autism... This ethical point of departure is symbolized by 'the iceberg philosophy'. For more information see [www.theopeeters.be](http://www.theopeeters.be)

# 9

**THE RIGHT of people with autism to appropriate counselling and care for their physical, mental and spiritual health; this includes the provision of appropriate treatment and medication administered in the best interests of the individual with all protective measures taken.**

As well as the formidable obstacles which their condition presents, people with autism experience the same problems as the other members of society and often in a more severe form. Problems such as bereavement, separations and movement from familiar surroundings are stressful for all of us but the effects can be devastating for those whose understanding is incomplete. Counsellors with an understanding of autism should be available to help, advise and support the person through the difficult periods.

In the same way, people with autism are liable to the same range of health problems as anybody else. Because people with autism are often unable to articulate any feeling on unhealthiness, carers must be particularly alert for any evidence of health problems. Routine health checks should be performed and the results recorded. Such monitoring should cover all the areas which would be covered in normal life. Tests should include checks on eyesight, hearing, dentition as well as direct medical areas such as blood pressure, cholesterol levels etc.

The fact that the person with autism does not complain or report ill health must not be taken as evidence of good health. Where problems are identified, the same standards of treatment should be applied as would be the case with the general population. Where medication is appropriate it should be correctly administered and the results monitored. Particular attention should be applied for potential side effects and where observed steps should be taken to eliminate them either by removing the medication; altering the dosages or, as a last resort, by giving other medication to minimise such effects.

The effectiveness of any medication must be reviewed regularly and any unnecessary, ineffective or perhaps harmful medication or treatment must cease or be withdrawn in the safest manner. Any medication, therapy or treatment should only be used when it is of direct advantage to the person with autism. Such treatments must never be given solely for the benefit of carers.

Although the capacity for a person with autism to comprehend the bases for religious faith may be impaired, observations suggest that such persons can benefit from exposure to religious experience. The opportunity for involvement in appropriate religious fellowship must be available. This must be especially true where the individual concerned or his family have expressed an interest in spiritual matters. The religious experience offered must, as far as is possible, coincide with the wishes of the person with autism or their family.

In the same way, people with autism should also have the right to opt out of religious experiences where such a wish is expressed by them.



# Reflections

## ***Professor Michael Fitzgerald***

### ***The Autism Perspective***

Persons with Autism have the right to have their mental health and care needs provided by people who are educated to understand the special mind-set of persons with Autism. It is critical that these mental health professionals understand the different perspective of people with Autism and the world that persons with Autism exist in. If these mental health professionals are not aware of these differences they will misunderstand persons with Autism and cause great distress to them. Treatments have to be given from an Autism specific perspective.

### ***Evidence Based Interventions***

The person with Autism has the right to evidence based treatment for their difficulties if at all possible. Unfortunately parents of persons with Autism have been bombarded with 'interventions' without scientific support which exhaust family resources as well as producing no evidence based benefit. Families of persons with Autism are massively committed and will try any intervention where there is a promise of benefit. Claims have been made for some interventions bringing about 'cure' which have led to massive disappointment being experienced by the families in the long run. The best hope for families with Autism in the long term is with the development of scientifically evaluated evidence based treatments. Therapies for autism without scientific support including hugging therapy, dolphin therapy, facilitated communication, secretin and chelation therapy. To this list can be added Bruno Bettelheim's in-patient psychoanalytic therapy where tragically mothers were blamed for causing autism by their behaviour. This was a tragic error in a condition which has a heritability of about 93%. Persons with Autism could not possibly benefit and must deteriorate when given dreadful aversives as a part of inappropriate behaviour therapy like the use of cattle-prods.

Persons with Autism have a right to orthodox multi-modal therapies. No single therapy ('one size fits all') is adequate for the treatment of Autism. It is a multi-faceted problem which requires multi-faceted interventions. These will include social skills programmes, programmes aimed at helping the person with Autism read other people's minds, behaviour therapy interventions, the TEAACH Programme which has a holistic orientation, actively involves parents and has structured teaching. Since communication skills problems are central to Autism speech & language therapy including pragmatic language therapy will be essential. Since Dyspraxia and sensory integration problems are so common occupational therapy will play a significant role. Medications have a role to play, particularly when all psychological and behavioural interventions have been unsuccessful. Persons with Autism are sensitive to medications and therefore lower doses are often necessary and can bring considerable relief of mental pain to the person with Autism. Antidepressants can sometimes be helpful if the person with Autism is severely depressed. Co-morbidity is a very common problem and medical treatments (combined with behavioural treatments) for ADHD can be helpful, although less helpful than when ADHD occurs without Autism. Bi-Polar Disorder, Schizophrenia and psychotic

episodes can co-occur and require antipsychotic medication. Unfortunately co-morbidities are often missed and therefore not treated which leads to a much reduced quality of life for persons with Autism, their families and indeed peers in classroom situations. It is critical that reasons for behavioural problems are first sought and remedied if possible before medication is used. Medication needs to be monitored and reviewed regularly. Of course this monitoring and review goes for all programmes of intervention. New technology should be used where appropriate. Persons with Autism have the right to long-term relationships with professionals and not to have to experience the upsetting event of incessant changes of professionals. The right of persons with Autism to informed consent for interventions including research and therapy is very important and must always be sought insofar as the person is able to give it. If not this must be sought from the guardians.

### ***Special Talents of People with Autism***

As well as training the person with Autism to read non-verbal behaviour, to learn to share and turn-take, to learn to set-shift, it is critical to build on the person's with Autism special talents whether musical, mathematical, mechanical or in the construction arena, and in the artistic arena more broadly. This building on talents can be best done in a social context where teaching social skills are done at the same time. Unfortunately in the past there was excessive focus on the deficit model of social skills and not sufficient emphasis given to talents including savant talent. It is critical that both of these are highlighted in assessments.

### ***Physical Care of Persons with Autism***

In terms of the physical care of persons with Autism it is important that the high pain threshold that persons with Autism sometimes have is taken account of by professionals providing clinical care which should be of a high standard. There is no link between the MMR vaccine and Autism and persons with Autism have the same right to vaccination as the rest of the population given under the guidance of medical professionals knowledgeable in this area.

### ***Individualized Interventions***

All providers of services for persons with Autism should act as advocates for the person with Autism or help these person with Autism who are able to advocate for themselves to do so more successfully. Providers of services should provide individualised treatments, in the least restrictive environment, with treatments appropriate to the persons intellectual level. They should engage in the development of appropriate individual family intervention plans with built in respite care where necessary. Mainstream schools should provide trained Special Needs Assistants and resource teaching where appropriate, or if the above is not possible because of the difficulties a child with Autism may have, then treatment in high quality special schools should be provided. Training the person with Autism to interact with and to meet pupils without Autism is important. Providers of services to persons with Autism need to protect persons with Autism from bullying, show them respect and not, for example, talk in front of them as if they were not present. They have a right to respect from a trained, enthusiastic, interested mental health providers. Persons with Autism have the right to have their spiritual needs provided for where they so wish. This can improve mental health where the person engages in the religious experiences of their choice. They must also have the choice not to engage if they do

not wish. Where appropriate they have a right to support and counselling with workplace skills which can lead to greater success in the workplace. The quality of the treatment of persons with disabilities is the best indication of the quality and depth of any civilisation.

*Professor Michael Fitzgerald*



Michael Fitzgerald is Henry Marsh Professor of Child and Adolescent Psychiatry at Trinity College, Dublin. He was the first Professor of Child Psychiatry in Ireland and has diagnosed over 2000 persons with ASD since 1973. He is involved in writing 18 books including Co Editing Handbook of ADHD published by Wiley. He has written a number of books on creativity including The Genesis of Artistic Creativity. He has extensive clinical experience with persons with ADHD children and adults.

# 10

**THE RIGHT of people with autism to meaningful employment and vocational training without discrimination or stereotype; training and employment should have regard to the ability and choice of the individual.**

As we become older it is natural to seek dignity and increased self esteem through work which is satisfying, interesting, worthwhile and within our capabilities. People with autism should have the opportunity to perform work which meets these same needs. Too often people with disabilities are required to perform meaningless and repetitive tasks which, apart from occupying time, have no ultimate function. The fact that people have difficulties in communication does not imply such a degree of stupidity that these tasks will become, in any way, rewarding. The enforced completion of actions which are obviously pointless is both confusing and degrading.

People with autism should have the opportunity to perform a variety of tasks and share in a variety of work experiences. Only when such a variety exists and people are aware of the options can there be any choice of activity. People with autism, because of their inherent difficulties, could require considerable help in performing relevant duties. Efforts should be made to teach and encourage them to attempt some new tasks which may, at first sight, appear challenging and beyond their capabilities. Ultimately tasks must be found which are appropriate to the abilities and accord with the desires of the individuals concerned.

Wherever possible, attempts should be made to seek employment within the community at large but, where this is attempted, considerable support for the individual and advice for fellow workers should be available. People with disabilities are often given the unpleasant, repetitive and dirty jobs which are avoided by other employees. Such discrimination must be avoided.

The activities of any individual must be reviewed regularly to ensure that they reflect the developing aspirations and abilities of the individual.

Even when a person with autism is apparently satisfied with his occupation, it may be appropriate to consider experience with an alternative. It may be that the person still prefers the original occupation and so the possibility of returning should exist.

All people with autism should have the opportunity to share in the running of their own “homes”. Although professionals may assist or supervise such tasks, residents should be involved, at whatever level is possible, in the cleaning, maintenance and food preparation in their own home as well as tasks concerned with their own cleanliness and clothing. Such work should not be left totally to nursing or domestic staff.

## Reflections

### ***Thorkil Sonne, Founder of Specialisterne and Specialist People Foundation***

#### ***The Right of People with Autism to Meaningful Employment***

The right to employment is one of our most fundamental rights. Through employment, we can achieve dignity and increased self esteem by performing tasks that are worthwhile and satisfying. Finding a place in society is often intrinsically linked to finding a job. However, for the majority of people with autism (Autism Spectrum Disorder), securing meaningful employment is often the biggest challenge they face as adults; a challenge that appears all the greater because, in many communities, support and focus on people with special needs decreases dramatically once they move from childhood to adulthood.

A meaningful and productive job that matches the skills and ambition of the individual gives people with autism a sense of being active contributors to society, as well as a platform to increase their self-esteem and quality of life. The key to achieving this is correct assessment of each individual's needs, abilities and specific talents.

The resources of people with autism can be either active or passive depending on how far or near they are to their specific comfort zone. Defining this comfort zone is tantamount to affording people with autism a fair chance to enter the labour market. Thus, we need to be able to assess their motivation, skills, learning profile, sensory issues, work environment issues and work-load capabilities in order to accommodate them and make them feel wanted in the work place.

Some people with autism will be able to work in mainstream businesses in tailored work environments whereas others will need sheltered work environments if they are to perform well and feel that they are in their accepted comfort zone. Some people with autism will be able to perform important assignments for the corporate sector at the same market terms as individuals without an autism diagnosis, whereas others will never be able to compete in this sector at normal market terms.

Regardless of the level of contribution, all individuals with autism must be met with both respect and accommodation. In doing so, we can best avail of their resources and help them to develop their vocational and life skills in accordance with the motivation, ambition and potential of each individual.

#### ***How can people with autism be an asset to the employer?***

The UN has committed nations globally to secure equal rights for people with autism – including the right to meaningful employment. However, true equality in society for people with autism can only be achieved if we change attitudes towards people with

autism. We need all the relevant stakeholders to join forces in giving people with autism the respect and understanding they deserve and need, so that together we can define how best we can help people with autism take an active and worthy role in the labour market.

There is a huge demand in the corporate sector for employees who can solve tasks that require a good memory, a structured mind, a passion for detail, an ability to identify patterns and spot deviances, and who are honest and loyal. It is my estimate that at least 5% of the daily tasks in any given business area, are suited to people with autism.

We need a massive shift in the corporate mind-set: that people with autism represent a potentially huge untapped pool of resourceful, skilled, innovative and loyal employees. The corporate sector also has to understand that they can only get access to this great untapped resource if they are willing to accommodate and respect people with autism. As aforementioned, competencies can be active or passive – it's all up to how you assess, prepare and manage people with autism. There will be some who will need a sheltered work environment in order to excel. But more will be able to work in traditional companies as long as they are accommodated and managed according to their specific needs.

### ***Show the way – Specialisterne as show case***

The most efficient way of changing minds is to illustrate how people with autism can participate in society – on equal terms – as long as they are met with respect and understanding. With this in mind, there are a growing number of small companies whose aim it is to bring the corporate sector and people with autism together. I founded the company Specialisterne (The Specialists) in 2004 in order to showcase how people with autism can solve valuable tasks for the corporate sector at market terms if given the right assessment and training. Since then, Specialisterne has been providing services, such as software testing, quality control, data entries and logistics, for corporate customers at market terms.

Specialisterne provides assessment and training for people with autism who have the ambition and the potential to become active and valuable contributors to the labour market. We help define a personal business profile for each individual, which includes defining where their talents lie, what roles they are best suited to, and what particular work environment settings are needed in order for them to excel. They then have the opportunity to become Specialisterne consultants. Most of our consultants work on the customer site. It is a crucial part of our role to prepare the customer for the special working relationship that our consultants often need to succeed. We tell our customers that when working with our consultants they need to be very clear in their expectation setting; they must never use irony to get their point across, to expect that our consultants say what they mean and mean what they say, and to ensure that the work environment has been adjusted to cope with any sensory issues the consultant may have. However, the most important commitment from our customer is the pledge to avoid causing the consultants any stress. For example, we agree with the customer that if they need to implement rapid changes, they must deal with our personnel manager at Specialisterne who will in turn deal

with the change request in a manner causing the least possible stress to our consultants.

The Specialisterne model has made it possible for people with autism to be included at the customer site in a tailored manner where the person with autism feels both wanted and understood.

### ***The Dandelion Model***

To most of us, the dandelion is an annoying weed. But it is also regarded as a valuable herb when cultivated. So, is it a weed or a herb? The plant is the same – the only difference is how much knowledge the person defining the plant has, and how much they are willing to cultivate it.

This analogy is also valid for people with autism. At Specialisterne, we see people with autism as valuable individuals worth cultivating, whereas society may see them as outsiders to be cast aside – people who do not fit into the norms of society. The message is that there are always two sides to the story when you look at somebody with autism – the herb or the weed. At Specialisterne, our logo is the dandelion seed, reminding us to always take the “herb” perspective and do our utmost to make people with autism feel wanted in the workplace.

Specialisterne has already achieved recognition in the corporate sector and been heralded by the Danish IT Industry Association. The company is also a Harvard Business School case study and has been recognised by the Wired Magazine as ‘One of 12 shocking ideas which can change the World’.

### ***Commitment to achieve global impact***

We want to make a global impact. And we are not without support. So far, people from over 60 countries have reached out to us, wanting to learn from the Specialisterne model and use it to help people with autism in their country. To help make this impact, I founded the non-profit Specialist People Foundation in 2009. Our vision is that societies around the world will respect and accommodate people with autism as valuable and contributing citizens. We use the term ‘Specialist people’ for our consultants, as we believe that they should be defined by their special personalities and abilities, rather than their diagnosis. The Specialist People Foundation has set a goal of enabling one million jobs for specialist people (people with autism and similar challenges) by replicating the Specialisterne model globally, and by inspiring and teaching social entrepreneurs and corporations to use our management model to hire and employ specialist people themselves.

### ***We can all become change makers***

The UN Charter of Rights is a crucial commitment from governments around the world to promote equal rights for people with disabilities. The UN has shown the way – but now we need a change in the way we view people with autism so that we can best implement the Charter throughout the world.



### ***So what can we do to help this process along?***

Too often, autism is seen as a cost to society and people with autism regarded as troublesome because they do not fit in. The 'weed' perspective is dominant. We need to see beyond the costs and the challenges. We need to find the 'herb' perspective and give people with autism a fair chance to identify their skills and ambitions. We need to understand how best we can make people with autism feel wanted, and help them excel in the labour market. If we can encourage all stakeholders to join us in choosing the 'herb' perspective on people with autism we can change society on a global scale.

The UN Charter of Rights is crucial to promoting the rights of people with autism, and employment is a very important factor to fully integrating people with autism into society. We all need to play a role to make this change happen. We need to work with schools and the authorities to prepare people with autism; to provide them with vocational and life skills to make the transition from unemployment to employment as smooth as possible. We need to make our employers understand how they can tap into this pool of skilled and loyal resources. We need parents and families to encourage loved ones with autism and help them see that they can have a valuable and interesting career in a workplace that understands their needs.

But most of all, we need people with autism to be ambitious about employment, to find their comfort zone, to be open to assessment and to identifying their special skills. We need to showcase and celebrate the successes, and to remember that being different does not have to be a disadvantage. And we need to remember that for people with autism, the criteria for successful employment differ from person to person. Some will be able to work alongside non-autistic employees in a mainstream work setting, whereas others will need sheltered work environments. Some will be able to solve very complex assignments, whereas others will only be able to perform less complex assignments. Let's celebrate diversity and work together to make the most of the UN Charter of Rights on employment.

*Thorkil Sonne*



Thorkil Sonne founded Specialisterne (The Specialists) in 2004 as a for-profit company where the skills of high functioning people with autism spectrum disorder are used to perform high quality services like software testing for corporate customers.

Specialisterne was awarded 'Best large social firm Europe 2006' by CE FEC.

Thorkil is chairman of the Not-for-Profit Specialist People Foundation which he founded December 2008 with Specialisterne as in-kind contribution.

The goal of Specialist People Foundation is to enable one million jobs for specialist people with autism and similar challenges on a global scale and thereby make societies respect and accommodate specialist people as worthy and valuable citizens.

Thorkil has a background in the private IT business, has been president of a local branch of Autism Denmark and is father of a son with autism.

Thorkil received the 'Autism Prize 2004' by Autism Denmark.

Thorkil is an Ashoka Fellow and participates in the Globalizer program.

# 11

## **THE RIGHT of people with autism to accessible transport and freedom of movement.**

Without accessible transport, the means to freedom of movement, life becomes a form of imprisonment. People with autism should have access to those forms of transport compatible with their requirement for mobility and their abilities.

Those with sufficient abilities should be encouraged to use the same forms of transport as the general population. Training schemes should be utilised to permit the use of public transport wherever possible. Sometimes it may be appropriate for persons with autism to utilise cars or bicycles and this should be encouraged where appropriate.

Some form of “mobility allowance”, which should be used for transport, should be included in any grant, pension or allowance which is provided by the public authorities or other funding agency.

Where means of transport are provided by service providing agencies, they should, as far as is practicable, be as similar as possible to normal vehicles. The use of ambulances or other prominently marked vehicles with an obviously institutional appearance is stigmatising to those being transported and reinforces the concept of “being different” which we are fighting to eradicate.

## Reflections

***Margaret Whelan  
Susan Day Fragiadakis***

Freedom of movement is a reflection of one of our most basic rights; a right to which all independent adults aspire. Freedom of movement is central to our right to participate in all aspects of our communities. For individuals with an Autism Spectrum Disorder (ASD), true freedom of movement requires accessible transportation. One of the central components of their opportunity to exercise their right to freedom of movement is the availability of accessible, suitable transportation options, and the support to learn the skills necessary to utilize these options. Together, accessible transportation and freedom of movement are essential elements for successful, active participation in community. They are symbols of independence and the right to choice.

When present and available, accessible transportation options and freedom of movement can have a profound impact on families, neighbours and communities. Access to suitable transportation options, with support that ensures success, increases our collective capacity to engage with members of our community, including those with an ASD, and to allow each to care about and respect the other. Near typical experiences, increased independence and greater engagement in our communities are goals shared by all families, and especially those with a child challenged by an ASD.

In the context of celebrating the “Charter of Rights for People with Autism”, it is our intention to provide two reflections: firstly, what must be in place to properly support individuals with an ASD to actualize their right to accessible transportation and freedom of movement, and secondly, a reflection on what this could have meant to a family with an almost senior citizen with ASD had he had supports available to provide him with the transportation options and true freedom of movement.

### ***Accommodations that Create Options***

Accessible transportation takes into account all modes of transportation: buses, trains, subways, cars, and, yes, even walking. While the availability of transportation options may be closely tied to proximity in both urban versus rural settings, successful access to any and all of these requires the same attention and commitment. Experience shows that the transportation needs and accompanying skills required for success, regardless of the level of independence of the individual with an ASD, are generally the last part (or the missing part) of the intervention, support and educational plans. It is often forgotten in the skill building process; often not factored into the cost of intervention plans. Its importance as a key factor in successfully achieving freedom of movement is often not recognized until much later in the learning and skill acquisition process, when acquisition may be more challenging.

To build skills and support for true freedom of movement and access to transportation options, the process needs to start early, not just as part of a transition

to adulthood plan or as a preparation for active participation in community activities once school has ended. Skill building to enable freedom of movement and access to transportation options needs to be embedded in support plans for young children and their families. These plans then need to be adjusted to reflect skill acquisition, age, maturation and suitable levels of independence.

Opportunities for teaching and training transportation related skills at an early age provide parents, family members, caregivers and community members with experiences of success that increase their awareness, confidence and comfort level, leading to increased independence and the exercise of the right to freedom of movement. By building transportation skills into early experiences an expectation is created – that access to transportation options promoting opportunities for greater freedom of movement is a lifelong goal. It is a long term investment in, and commitment to, an optimal quality of life. By providing children, then young adults and finally adults, with opportunities to practice using accessible community transportation options, we provide them with four essential skills:

- Planning – incorporating transportation into the plan for any activity of daily living;
- Problem solving - providing opportunities to make changes based on the real experiences associated with the vagaries of transportation;
- Choice making – building the capacity to select activities and destination based on available transportation options, and
- Risk taking – providing individuals with an ASD with the dignity of making a choice that may not always be as safe as a caregiver might prefer, but contains a level of risk that enhances their learning, future independence and decision making.

To provide maximum opportunities for success, accommodations will be needed. They include but are not limited to the following:

- Informed staff and passengers on public transit;
- Opportunities to practice, with support and instruction;
- Increased use of visual cues to support planning and decision making, such as well marked stops and stations;
- ‘Quiet’ cars on trains and subways where loud talking, cell phones, music, etc. is prohibited;
- Subsidies to enable the use of taxis, where the drivers are sensitive to the need for a quiet drive;
- Head phones to filter sounds, provide soothing music or calming messages;
- Hand held computerized tools/smart phones to provide written cues to the transportation sequence or alternatives in the event of unforeseen changes to routes;
- Frequent walking/cycling, with support, to desired destinations, increasing comfort and familiarity;

- Practice, with variable, declining support to ensure successful route completion;
- Ability to work off peak hours to avoid the hectic rush hour experiences of most public transportation systems;
- Ability to participate in carpooling;
- Volunteer drivers;
- Shared transportation schedules among caregivers;
- Availability of specialized transportation vehicles, without labels, that are more reflective of options that most individuals might experience;
- Significant advance notice of novel transportation options, such as planes, ensuring sufficient time to understand what is expected and practice the routine;
- Funding allowance in the intervention plan that enables appropriate support for transportation;

We have not addressed the issue of gaining a driver's permit. There can be no doubt that in many communities there is considerable social validation in successfully acquiring one's driver's permit. A small segment of the ASD population will aspire to this goal as well. However, in addition to learning the mechanics of driving a car, there must be an assessment of capacity in the area of self-regulation and anxiety before proceeding on this course.

The road to optimal independence, regardless of the level of support required, demands accessible transportation options. When presented with viable transportation options, freedom of movement becomes not just a possibility, but an attainable right.

### ***A Family Perspective***

***by Susan Day Fragiadakis***

I am writing as the sibling of a 57 year old man with autism who in his own way is an amazing success story to the people who love and admire him. The world that people with an Autism Spectrum Disorder are being born into today has changed dramatically since my brother was born in 1954 in London, Ontario, Canada. He received the diagnosis in the era of the "refrigerator mother", when so much time and effort was wasted blaming the parents rather than providing education and support. My brother was not included in the school system, nor were community supports available. My parents figured things out on their own, with my sister and me helping as much as children can.

When we were children we lived in a variety of rural and small urban communities, moving as my father's career dictated. Accessible transportation for my brother usually amounted to us walking, riding bikes and being driven in the family car. Rick has always loved to walk and ride his bike but can be inconsistent in his attention to traffic and other hazards. I think if he had a choice he would walk, ride his bike and ice skate everywhere if he could. It seems that these modes of movement give him a

sense of freedom and a degree of control and independence, even though he must do these with another person to assist him with safety awareness.

That is not to say that Rick does not like being in a vehicle – my sister and I always joked that he was watching us learn to drive and we hoped someday he did not just jump in to the driver's seat and drive better than we could (as happened when I got my first bike and he suddenly rode away on it with no-one ever teaching him how to ride). The motion of a car soothed him as a distressed baby, involved him in family outings and activities, and now as an adult he feels the front passenger seat (the "grown up person's seat") is his!

My mother and I have been his primary sources for transportation. More recently, he is now being a passenger with the next generation of our family as his nieces have recently started to drive. So now Rick is a man entering his late 50's whose freedom of movement is still restricted by the availability of others to help him with transportation. He currently lives in a group home in a small rural community, 1 hour from his mother who is in her late 80's and 3 hours from my house. Rick has always come to one of our homes every 2-3 weeks, alternating between Mom's and my house. Mom and I have always driven him to and from our homes for these visits, even with our tricky Canadian winters. Given that Mom is in her late 80's we are so lucky she is still such a confident driver, but the winter driving is starting to concern her. Alternatives are few – even if there was a bus service (which there is not) currently Rick does not have the communication or safety skills to use buses without a companion.

Would this difficulty accessing and utilizing accessible transportation independently be the case if he had been included in the education system and if community services had been available? We can only speculate. My family did do a wonderful job having him develop a love of being physically active and experiencing a degree of freedom of movement – walking, riding a bike, skating, snowshoeing, etc. Where we could have used assistance is in safety skills, functional communication and other skills that could have led to using transportation and mobility options with more independence. If these supports had been available from a young age we might not be in our current quandary regarding transportation to continue Rick's visits with the family. As has been the case since Rick's early days, our family is in a situation of creating services that are currently not available – now in relation to accessible transportation for older adults with an ASD who have aging family members.

I feel very strongly that training related to all aspects of transportation and mobility must be a core part of the support available to families and individuals with an ASD. This support must begin at a very young age so that as adults individuals with an ASD can achieve the level of independence they are capable of. This will ensure their ability to participate fully in their community – recreationally, socially, living arrangements, and accessibility to employment opportunities. My brother has achieved so much with the limited support he was offered. With reasonable transportation options and support, his freedom of movement would have been so much more significant and fulfilling. Our dream is that the generations that have followed him will have the full range of support that he did not have access to. This is a human right that is must be available to all individuals with an ASD!

*Margaret Whelan*



Margaret Whelan has recently retired from her lengthy tenure as Executive Director of Geneva Centre for Autism in Toronto, Canada. Margaret has been an active member of many advocacy groups promoting the rights of individuals with an ASD. Her work includes founding member of Canadian ASD Alliance; Autism Society America Professional Advisory Council member; editorial board of Focus on Autism journal; member of World Autism Organization, and regular participant and promoter of Autisme Europe.

*Susan Day Fragiadakis*



Susan Day Fragiadakis has recently joined the Autism Research Centre at Holland Bloorview Kids Rehabilitation Hospital in Toronto. Previously Susan was a clinician and training institute faculty at Geneva Centre for Autism for many years , and is the sibling of a man with autism who is in his 50's. Susan participates as a professional and sibling representative on committees through Autism Ontario. As well, she has written articles for various publications related to family and sibling concerns.



# 12

## **THE RIGHT of people with autism to participate in and benefit from culture, recreation and sport.**

People with autism need relaxation just as much, if not more, than non-disabled people. A range of activities which cater for individual needs and inclinations should be provided. A variety of activities which includes participation in, as well as observation of, culture, entertainment, recreation and sport is vital. Individuals should be invited and encouraged but not forced to participate in such activities. Very often a degree of persuasion may be necessary because of a lack of confidence resulting from the autism itself.

Whilst recognising that some activities are best suited to a closed environment, wherever possible the utilisation of outside facilities and involvement of non-disabled people is advocated.

Such activities should be interesting and varied. The mere repetition of rituals and other meaningless activities is neither stimulating nor therapeutic. People with autism can benefit from exposure to high quality art, music and other creative activities.

# Reflections

***Dr. Samira Al-Saad***

## ***Introduction***

The RIGHT of people with autism to participate and benefit from cultural, entertainment, recreation and sport.

Cultural, recreational, leisure and sporting rights are an integral part of human rights and, like other rights, are universal, indivisible and interdependent. The full promotion of and respect for those rights is essential for the maintenance of human dignity and positive social interaction between individuals and communities in a diverse and multicultural world.

It implies a commitment to human rights and fundamental freedoms for person with Autism, and requires the full implementation of those rights. While compliance with the declaration is mainly the responsibility of States, all members of civil society are expected to comply including individuals, groups, communities, minorities, indigenous peoples, religious bodies, private organizations, business and civil society in general.

## ***Culture***

The following are necessary conditions for the full realization of the right of persons with Autism to take part in cultural life on the basis of equality and non-discrimination:

*Participation* covers in particular the right of persons with autism – alone or in association with others or as a community – to act freely, to choose his or her own identity with guidance, to engage in one's own cultural practices and to express oneself in the language of one's choice. Everyone also has the right to seek and develop cultural knowledge and expressions and to share them with others, as well as to act creatively and take part in creative activity. Cultural participation requires access to cultural inheritance, to information and the freedom to create, transform, show and trade cultural works and techniques, whether in school or in community events.

*Access* covers in particular the right of persons with Autism – alone, in association with others or as a community – to know and understand his or her own culture and that of others through education and information. Everyone has also the right to learn about forms of expression and dissemination through any technical medium of information or communication, to follow a way of life associated with the use of cultural values and to benefit from the cultural heritage and the creation of other individuals and communities. The States and civil society should ensure that persons with Autism have the opportunity to utilize their creative, artistic and intellectual potential, and not only for their own benefit, but also for the enrichment of their

community, and that States should promote accessibility to and availability of places for cultural performances and services.

*Availability* is the presence of cultural goods and services that are open for persons with Autism to enjoy and benefit from, including libraries, museums, theatres, cinemas and sports stadiums; literature and the arts in all forms; the shared open spaces essential to cultural interaction, such as parks, squares, avenues and streets; nature's gifts, such as seas, lakes, rivers, mountains, forests and nature reserves; intangible cultural goods, such as languages, customs, traditions, beliefs, knowledge and history, as well as values, which make up identity and contribute to the cultural diversity of individuals and communities taking into consideration the structure needed to be understood and comfortable for a person with autism.

*Accessibility* consists of effective and concrete opportunities for persons with Autism and their families to enjoy culture fully, within physical and financial reach for all in both urban and rural areas, without discrimination. Accessibility also includes the right of persons with Autism to seek, receive and share information on all manifestations of culture in the language of the person's choice, and the access of communities to means of expressions and dissemination.

*Acceptability* entails that the laws, policies, strategies, programmes and measures adopted by the State for the enjoyment of cultural rights should be formulated and implemented in such a way as to be acceptable to the persons with Autism and their families. In this regards, consultations should be held with the persons with Autism and their families in order to ensure that the measures to protect cultural diversity are acceptable to them.

*Adaptability* refers to the flexibility and relevance of strategies, policies, programmes and measures adopted by the State and civil society in any area of cultural life, which must respect the cultural diversity of persons with Autism and their families.

*Appropriateness* refers to the realization of a specific human right in a way that is pertinent and suitable to a given cultural modality or context, that respects the culture and cultural rights of the individuals and communities, persons with Autism and their families. The need to take into account, as far as possible, cultural values attached to, inter alia, food and food consumption, the use of water, the way health and education services are provided and the way housing is designed and constructed. States and civil society should ensure that persons with Autism have the opportunity to utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of their community, be they in urban or rural areas, and that States should promote accessibility to and availability of places for cultural performances and services that fit their needs.

In order to facilitate participation of persons with Autism in cultural life, States and civil society should, inter alia, recognize the right of these persons with their families to have access with their families to cultural material, television programmes, films, theatre and other cultural activities, in accessible forms; to have access to places where cultural performances or services are offered. States and civil society should recognise the right of persons with Autism to take part on an equal basis with others

in cultural life, and shall take all appropriate measures to ensure that persons with Autism:

- a. Enjoy access to cultural materials in accessible formats;
- b. Enjoy access to television programmes, films, theatre and other cultural activities.
- c. Enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance.
- d. States and civil society shall take appropriate measures to enable persons with disabilities to have the opportunity to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society.
- e. Persons with Autism shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.

### ***Sports***

As sports is one of the important keys to empower all including people with Autism and its importance to their communication and inclusion with society. States and civil society should recognize the rights of persons with Autism to take part on an equal basis with others in sporting activities, and should take all appropriate measures;

1. To encourage and promote the participation, to the fullest extent possible, of persons with Autism in mainstream sporting activities at all levels;
2. To ensure that persons with Autism have an opportunity to organize, develop and participate in sporting activities and, to this end, encourage the provision, on an equal basis with others, of appropriate instruction, training and resources;
3. To ensure that children with Autism have equal access with other children to participation in sporting activities, including those activities in the school system. Accessibility includes physical, attitudinal, resources, information and communication.
4. To ensure that persons with Autism have access to services from those involved in the organization of sporting activities.

### ***Recreational and leisure***

With a view to enabling persons with Autism and their families to participate on an equal basis with others in recreational and leisure activities, States and civil society shall take appropriate measures to encourage and promote the participation, to the fullest extent possible, of persons with autism and their families in recreational and leisure activities in mainstream activities at all levels;

## **Conclusion**

- The decision by a person whether or not to exercise the right to take part in cultural life individually, or in association with others, is a cultural choice and, as such, should be recognized, respected and protected on the basis of equality.
- States and civil society should identify appropriate indicators and benchmarks, including disaggregated statistics and time frames that allow them to monitor effectively the implementation of the right of persons with Autism and their families to take part in cultural recreational, leisure and sporting life, and also to assess progress towards the full realization of this right.
- States parties and civil society should recognize and promote the essential role of bilateral, regional cooperation in the achievement of the rights persons with Autism and their families, including the right of them to take part in cultural life, and should fulfill their commitment to take joint and separate action to that effect.
- To allow and encourage the participation of persons with Autism and their families in the design and implementation of laws and policies that affect them.
- Taking appropriate measures to conduct public campaigns through the media, educational institutions and other available channels, with a view to eliminating any form of prejudice against persons with autism and their families.
- Persons with autism should remain integrated in society, and their families should participate actively in the formulation and implementation of policies that directly affect their well-being and share their knowledge and skills with other families.
- The State and civil society should support programmes aimed at providing persons with Autism with easier physical access to all cultural institutions.

*Dr. Samira Al-Saad*



Dr. Samira Al-Saad a mother of a daughter with autism, is the Founder & Director of Jeddah Center for Autism (1993) and Kuwait Center for Autism (1994), & also the Founder & Head of Gulf Autism Union (since 2002). She had Master Degree in Special Needs from USA & Ph.D. from Leicester University in UK. In addition of establishing a specialized training Center for children with Autism which functions throughout the year serving different ranges of children with autism through different programs, Dr. Al-Saad is also an active research worker in the field of special needs with many of her research works published in scientific journals and presented/released in conferences.

She is an accomplished writer and translator contributing books on Autism to Arabic literature as well as the Founder & Editor of the first specialized periodical in Autism & Special needs – “Silent Scream” newsletter distributed in the whole Middle East since 2002. In 2007, she received the Kuwait’s first Corporate Social Responsibility award for her whole-hearted, enduring & persistent efforts for Kuwait Autism Society. Her sincere commitment to Autism field has earned her professional membership in International Autism Society, Rehabilitation International, Executive Committee of World Autism Organization, Kuwait Handicapped Society, Islamic Council for Disability & Rehabilitation in Riyadh and Committee of the Higher Council for Handicapped in Kuwait. Dr. Al-Saad is the Founder & the Head of Kuwait Autism Society (2006).

She won the prize of U. A. M. Women Society (U.A.E.) in 2003, the prize of the Ideal Mother (Kuwait) in 2006, Jaber Prize for Quality Management for the category of the best establishment run by a Lady (Kuwait) in 2008 & Jan Amos Comenius Medal for 2008 from UNESCO for her work as educator who have made a significant contribution to the development of education in autism field. Prince Salman Bin Abdul Aziz of Riyadh (Saudi Arabia) award for 2010 for her effort in establishing programs for Autism in GCC region.

## **THE RIGHT of people with autism to equal access of and use of all facilities, services and activities in the community.**

One of our main objectives is to allow and encourage people with autism to take their rightful place in society. Access to all the facilities available to normal society is a prerequisite if such objectives are to become a reality. The barriers which prevent active involvement are largely a result of misunderstanding.

On the one hand, the general public have a fear of all forms of disability and need to be reassured, through education and increased awareness, that people with autism will present no threat and can, through their participation, enhance their own enjoyment of any activity. On the other hand parents, carers and the people with autism themselves must accept the challenges which normal life presents. People with autism should not be prevented from attempting activities through over protectiveness or timidity. Experience has shown that, given appropriate encouragement and instruction, people with autism can accomplish much which would, at first sight, appear beyond their competence.

Embarrassment, awkwardness and confusion are less common in the person with autism than in carers, the general public and onlookers. Such responses will only be eradicated through experience, explanation and familiarity.

Without the right to use the range of facilities and services available to the rest of the community all education and training is pointless.

# Reflections

***Margaret M Golding.***

An open and democratic society is based on human dignity, equality and freedom. For example the Bill of Rights incorporated in the South African Constitution states that 'equality includes the full and equal enjoyment of all rights and freedoms' and that no person may unfairly discriminate directly or indirectly against anyone on one or more grounds including race, gender, sex, etc and disability.

Equal access to and use of facilities, services and activities in the community is essential if people with Autism Spectrum Disorder (ASD) are to become visible and respected members of their communities, and to have the choice of life-long learning and the development of independence.

However with Rights come Responsibilities and it is important that those working with and supporting children and adults with ASD and their families, provide them as far as possible with the skills needed to access community resources. From the start Education has to focus on functional learning so that the implementation of skills learned will assist the person with ASD to access facilities and services successfully.

The following historical account highlights the development of a perception that children with ASD would become adults with ASD, whose rights would need to be articulated and upheld. Fifty five years ago I met my first child with autism, Paul, in a small residential school newly set up by the London County Council for orphans and young children who had been institutionalised. We were far from thinking or talking about 'Rights' then. With Paul we were just puzzled about what we were looking at. He did not respond to the developmental syllabus which was so successful with the other children. He screamed when others came near him. The staff were unable to potty train him and became very frustrated because he did not respond to any verbal instructions. He was seen as 'naughty' 'attention seeking' and 'totally impossible' and staff became more and more negative towards him. The word 'autism' had not yet come into common usage, instead, the terms 'childhood psychosis' and 'childhood schizophrenia' were often used to describe such children. It would be almost twenty years until these children had rights to education in the UK, and in many other countries even today, this is not guaranteed.

In the late 1950's a specialist children's hospital called High Wick was set up by the mid- Herts. Hospital Management Committee in the UK to accommodate and research this condition which was then being described by Dr Mildred Creak and others as 'Childhood Autism'. The emphasis was on clarifying diagnosis and in 1961 a working party produced nine diagnostic points which made it possible for psychiatrists to start identifying children with this disorder.

*No one at this time had any idea that children with autism would grow up to be adults with autism!*

Autism was almost wholly in the medical domain and seen as a psychodynamic disorder i.e. a result of poor or faulty parenting particularly on the part of mothers.



Dr Leo Kanner in the USA who used the term ' Infantile Autism' had first focused on this aspect of family pathology, suggesting that his sample of mothers may have had an 'intellectual' approach' towards rearing their children, and the term 'refrigerator mothers' came into use. Parents were seen as the cause of the autism instead of its victims. Sadly these beliefs persisted for decades and probably set back research for at least twenty years. Even today in some areas, faint echoes of this perception can be heard in the terminology used by some professionals "these parents" etc. (i.e. no names used)!

As a young teacher I was approached by the Matron of High Wick who asked me to take up a teaching post which had been granted by the Education Authority. I received quite a surprise when Paul was referred to High Wick some months later, but I realised that his difficulties had been understood and he was now in the right place where a different approach to learning and teaching was possible.

*So in these early years, rights to access of facilities in the community was never on the agenda as it was thought that the children should be kept in a secure and specialised hospital environment.*

Gradually things started to change at High Wick. The famous Anna Freud who was then at the Hampstead Clinic began to question the value of psychotherapeutic interpretations for children who could not play symbolically. The Medical Superintendent, Dr George Stroh, began to take an interest in education stating that in Freudian terms it built up the ego or personality and that he could observe progress in the children's abilities to learn. Dr Louis Minski, the psychiatrist for the deaf in the UK, identified children with autism who had been placed in institutions for the mentally retarded and pleaded their case with the then Ministry of Education, stating that they were not mentally retarded but had a right to education. The result was a pilot venture, the setting up of a school for the children to see whether they could benefit from education. If so, the Ministry promised to advise local authorities accordingly. The school, Edith Edwards House, was supported by the Invalid Children's Aid Association (now called 'I Can') and pioneered a twenty four hour curriculum which focused on individualisation and building relationships with each child. Paul arrived from High Wick and continued his education in a real school in the community! In the meantime the National Autistic Society was also pushing for the right to education for children with autism and started its own school run by Sybil Elgar from her home in London.

*By the 1970's the rights to education for all children were established in the UK and since that time specialised education for children with autism has continued to grow.*

This specialist education, incorporates approaches empirically researched which reduce barriers to learning for these children, such as the T.E.A.C.C.H. approach (Treatment and Education of Autistic and related Communication handicapped Children) developed by Eric Schopler and Gary Mesibov at the University of N. Carolina USA. Eric Schopler had identified the good visual skills of the children he worked with and this informed our decision to incorporate AAC (Alternative and Augmentative Communication) into the curriculum. One such approach, Makaton, using signs, symbols and normal grammatical speech suddenly enabled us to give

our speech and language meaning by making it visual. Later, the development of PECS (The Picture Exchange System) further enhanced and clarified communicative intent.

*The development of visually structured communication enabled more learners with ASD to be involved in community activities such as work experience where the employers were helped to use visuals in the work place.*

The curriculum within the schools was now informed by Lorna Wing and Judy Gould's Camberwell study which identified the Triad of Impairments as being in the social, communication and imaginative areas. Educators began looking at the strengths which could enable the individual to achieve in the teaching and learning situation. The immense difficulties particularly in the area of social interaction began to become apparent through the writings of more able people with autism such as Prof Temple Grandin, Donna Williams, and films such as 'Rainman'. In the specialised schools we began to realise the importance of individualisation because of the different ways autism was a barrier to learning in each individual.

*Towards the end of the twentieth century in the UK, parents and professionals suddenly woke up to the fact that these children with autism were now adults with autism and were often ill prepared for the real world.*

The National Autistic Society and local Societies had set up Adult communities, and parents battled to get their sons and daughters rights to funding for specialised adult placements recognised. As Headteacher of a specialist school in London, I and my staff received a 'wake up call' when we visited some of our ex-pupils in an autistic community and were told that they were very compliant but did not do anything!! This astonished us as we had taught self help skills to a high degree and knew that our students were able to cook, clean and generally be adept at domestic tasks etc. What we had not done was to ensure that they could take responsibility for their own work and learning and we began to realise that we must go beyond compliance and enable our learners to manage their own agenda without being dependent on their educators for instructions and cues. More and more of our ex students were being placed in Care Homes in the community and we realised that schools were not doing enough to assist our learners to access the facilities and services in the community in a positive way. We began to focus on the functional aspects of learning and implementation outside the school in the community. This again was a learning curve. We also began to be aware of how complex a simple situation could be for our children with autism. Consider the case of Paul. He was now a teenager and we were helping him to travel independently. Our approach to implementing skills in the community was threefold. We would teach the skills, then shadow the person and finally get the student to teach the teacher. If step three could be accomplished we knew the learner had successfully internalised the skills and had the confidence to act independently. But we learned other things along the way. Paul was now at the second stage of learning to travel on the train (and I was shadowing him in the next compartment). He had been as a young child unable to bear being touched or hugged or to respond to other people's overtures being sensorily overwhelmed. Gradually he had become able to show emotion and express it and we were all delighted that he seemed a much warmer human being. We had however forgotten

to teach him what was age appropriate social behaviour. In the train he chatted to the lady sitting opposite him, telling her that he was coming to tea with me and reading aloud the names of the stations ( not usual behaviour for a large teenager). When he finally arrived he stood up and flung his arms around the lady saying "We're here"!!

*Oh dear –the travelling skills were fine but we needed to work on the social aspects i.e. what was fine at three or four years of age was not fine at sixteen!!*

*So we had finally learned that with Rights come Responsibilities and that we should not just educate in order for our students to claim equal rights but that we must educate them to be aware of their responsibilities in accessing facilities in a socially appropriate way.*

It is never too early to start and so, sitting down with staff working with young children, we began to analyse skills needed for common social occasions. For instance parents of our three/four year olds reported that their children with autism had been invited to a birthday party usually only once! This seemed like a good place to start. So we identified the skills needed to successfully manage a birthday party e.g. sitting - on a chair, on a bench, on the floor: eating from a plate (preferably your own!) be it china paper or plastic: drinking out of a cup or a beaker or with a straw: learning a party game e.g. 'pass the parcel': tolerating balloons or squeakers, and finally, learning to say or sign 'Thank you'. We later added the ability to accept a party bag when given i.e. not to just drop it or refuse it! Initially the parties were held in the classroom but in year two the first brave parents hosted their children's parties at home. So successful was this that they were all still having parties in their children's teenage years and adapting to changes in party routines.

As a trained counsellor I began to realise that there was a need to assist our learners to understand and manage their autism so that they became aware of their differences and could develop some insight into social rules and behaviours. Research into 'Theory of mind' had helped us to understand that one reason for our students' social difficulties was that they could not easily put themselves into someone else's place or see themselves as other people saw them. So for the next seventeen years we worked with our school leavers in a weekly counselling group. Techniques were adapted to raise awareness of each other e.g. the opening question was "What was good for you this week?" We adapted this so that the individual would be asked "What was good for him this week?" identifying another student, thereby helping the learner to put himself 'in someone else's shoes' and speak for them. Thus they were able to learn cognitively what other children absorb almost 'through their skin' at an early age. The emphasis was on developing self esteem and confidence. One session was always on 'compliments' spelling out what these were. The task was then for the student to ensure that during the next week they paid at least three compliments to people in the group. In the ensuing feedback students were asked how it felt, both to pay a compliment and to receive one. Having developed this skill students often endeared themselves to people by paying appropriate compliments and of course it had the effect of helping them to be more aware of others.

A range of social skills were tackled to enable the learners to deal with life outside a school environment. We had learned that people with autism were often the victims of bullying and one of the counselling sessions dealt with name calling. Asking the group to say what names they had been called gave us a real shock. The flip chart included all the usual insults heard in the street or in a school playground but then the students began to quote statements made by medical teams within their hearing, some of which were extremely negative. In quoting one of these statements about the child being a 'vegetable', his mother said " But he was only three years old at the time and did not have language". Other quotes were from staff in my own school who sometimes forgot that talking about a child in his hearing could be a negative experience.

*The value of support groups for adults with autism cannot be stressed enough.*

Here they can discuss their successes or otherwise in accessing facilities and services in the community and how this could be better managed. The technique of more able people speaking for less able means that everyone on the spectrum can be included and experience has shown that people with severe autism are equally committed to attending group sessions.

*But education regarding rights and responsibilities is not just indicated for the individuals with autism. The general public need to be informed and aware of the nature of autism and particularly have a realistic and empathetic understanding of how difficult social situations can be for people with autism and how they might respond.*

So education has to be extended from the school to the wider community. Schools have to familiarise their local communities with the nature of autism. We were able to link up with the local high school and foster inclusive activities where pupils visited each others' schools. Many children with autism have never set foot in a mainstream school and so lack understanding of other children's' life experiences.

The education of learners with autism is very specific. It needs the learning and teaching environment to be visually explicit but most important of all, experience has taught us that the focus should be on the strengths of the individual with ASD as this is how we enable them to understand and manage their autism and their lives in the community.

For decades the media, fundraisers and marketers have focused on the negative aspects of ASD, often being interested only in the challenges faced by parents dealing with children who have extreme problem behaviours.

*It is suggested that a focus on some of the strengths of people with ASD may help to overcome some of the fear of disability in members of the general public, stir their interest and reassure them that people with ASD can and should enjoy community services and facilities.*

Only then can we truly build bridges between the culture of autism and the neurotypical world most of us live in.

*Margaret M. Golding*



Margaret M. Golding is an Educational Consultant in Autism and for the last decade has worked mainly for Autism South Africa assisting in the development of schools across various cultures.

Margaret has more than 50 years experience of Autism and has been a Principal of six schools for learners with autism in the UK and South Africa. Her 'hands on' models of training include the TEACCH approach in conjunction with Prof Gary Mesibov of the University of N Carolina and the establishment of Makaton South Africa.

Her qualifications include an MA in Education and Psychology, Advanced Diploma in Special Education, Psychiatric Diploma in the Management of Psychotic and Emotionally disturbed children and Certificate in Counselling as well as a basic teacher's diploma and qualifications in Educational Management.

Her experiences included a 3 year Fellowship in the Centre for Autism Studies at the University of Hertfordshire UK, two years assisting in the development of an advisory service supporting children with ASD in mainstream schools in Hertfordshire and developing and delivering post grad courses for serving teachers both in the UK for Greenwich University , and South Africa. She has undertaken training in several countries including Greece, Hungary and Kuwait.

Margaret presently serves on the Governing Body of the Vera School for Autistic learners in Cape Town and is a Trustee of Hurdy Gurdy House, a facility for young men with ASD needing high support in Cape Town.

[mmgolding@vodamail.co.za](mailto:mmgolding@vodamail.co.za)

# 14

## **THE RIGHT of people with autism to sexual and other relationships, including marriage, without exploitation or coercion.**

The rights of people with autism should reflect precisely those available to the rest of the population. They should reflect the legal situation and social customs currently prevalent in the country concerned. These rights should take particular account of and be responsive to the particular nature of the difficulties which autism presents.

Particular attention should be applied to the wishes of the individual. It is sometimes not difficult to persuade a person with autism to voice a certain decision even when it is clearly against their natural inclination. In order to avoid the possibility of coercion through this mechanism, carers should ensure that any participant with autism is aware of the consequences of their decision and actions. Similarly, it may be difficult for a person with autism to enjoy any form of relationship without encouragement and support from carers who are sensitive to the problem of autism.

Many people with autism, particularly those who are more severely afflicted, show little interest in sexual relationships and will consequently show little interest in such activities. Others will show interest but will lack the communicative and social skills necessary to express their interest and desires. Advice and encouragement will almost certainly be necessary for the attainment of successful relationships. The necessary support should be available.

Informed and sensitive advice on birth control and genetic counselling are necessary. Where marriage takes place, the partners should not be separated but be encouraged to live together in the normal way.

Where a person with autism demonstrates the desire for sexual activity yet, through a failure to understand the correct social conventions, is awkward and unable to achieve his or her objectives, the use of powerful hormonal drugs which diminish libido is inappropriate. Such actions should only be considered where there is a definite risk of a serious criminal assault by the person.

## Reflections

***Gary B. Mesibov, Ph.D.***

The rights of people with Autism Spectrum Disorders (ASD) should reflect the rights of society in general. This is a basic tenet of The Charter of Rights for People with Autism and is an important priority for all those who care about this group. In addition, rights, activities and privileges should also reflect the wishes of each individual. This balance between general rights and individual preferences is especially important when it involves their rights to their own sexuality and personal relationships with other people because there are so many individual differences related to the complex issues involved with this and many people are not totally comfortable thinking and discussing the issues. In the area of sexuality and relationships, there is enormous variability among individuals with ASD. Some are not inclined towards any involvement with others and have little interest in sexuality or intimate relationships of any kind. At the same time for others these relationships are extremely important and their needs are compelling. While considering the rights of people with ASD we must include the right to very limited involvement in relationships with others as well as the right to support, assistance, and information to help them become totally involved with others both sexually and personally. While trying to respect the individual skills and needs of people with ASD, this paper will discuss some of the general issues and skills needed in this area, some of the special problems that autism presents in meeting individual needs, and some of the particular vulnerabilities of this population in these areas.

When thinking about sexuality and interpersonal relationships there are a wide range of aspects to consider. These include:

- Privacy issues in terms of respecting others privacy as well as conducting oneself properly in public by knowing what are private activities for oneself to engage in and where to engage in these private activities;
- There also are a range of basic biological issues relating to reproductive health, contraception, and sexual responses;
- As individuals progress questions of dating, stages of relationships, and partner sex should be addressed;
- Individuals need to be aware of the above specific issues as well as societal attitudes and values related to them;
- Those involved in close sexual relationships need an understanding of partnered sex;
- Additional issues that involve intimidation and aggression.

Those working with people with ASD should be familiar and comfortable with all of these issues although every one of these issues will obviously not involve each of the people that they serve.

Because sexuality is a complex issue in our society parents should be involved in the program planning. Families are usually the ones who guide their typical children

through these issues so they should be the starting point for those with ASD. Because sexuality is an important part of life, even though many are not comfortable talking about it, a family does not have an option of ignoring it with their child with ASD. If they do not feel comfortable discussing these issues with their child on an ongoing basis in a comprehensive way then it is incumbent on them to find someone else who can do it. People with ASD, at any level of functioning, will not be able to get the information they need in this crucial area if there is not someone to provide assistance and information in a meaningful and very concrete way. Some of the things that make it more difficult for people with ASD to exercise their rights to sexuality and heterosexual relationships include:

- People are uncomfortable talking about these issues so often ignore them thus forcing those with ASD to deal with the issues themselves;
- Society is uncomfortable with these issues so when these questions and issues are raised most people are not likely to follow up on them;
- Professionals often fear that they might get in trouble if they work on guaranteeing these rights openly and assertively with their clients with ASD;
- People with ASD are often uncomfortable with these issues so are less likely to raise them as part of their own self-advocacy efforts than they are to raise other issues.

Another problem in this area is the potential for others to take advantage of people with ASD in the area of sexuality and intimate relations and also to abuse them. People with ASD can often be manipulated and placed into compromising positions in intimate relationships with others and these situations are often the hardest for parents and advocates to deal with. Balancing the rights of people with ASD with protecting them from harm can be delicate in the best of cases and especially difficult in situations that are less than ideal like those related to sexual exploitation. Finding that delicate balance and knowing how to handle it can be a real concern for many.

Another major reason that the situation is not better than it is and not up to what it must be is because our current health care delivery system is inadequately responsive to the sexuality and intimacy needs of people with ASD, and most training programs for health professions fail to provide the knowledge and skills clinicians need to provide any kind of special care to people with disabilities. People with disabilities usually lack the knowledge and strategies they need to promote sexual personal health and assistance on intimate relationships. Additional goals to help improve these skills so that health professionals can be of more assistance might be:

- To promote and exchange knowledge and information among health care providers to develop best practices that will improve and/or increase positive health care outcomes for people with ASD;
- To promote empowerment of people with ASD to take charge of and advocate for their own health and sexuality needs;



- To develop relationships and cooperation among organizations and professionals concerned with health issues related to ASD;
- To identify gaps in research and formulate recommendations for future research, practice, education, and policy to positively influence the lives of people with ASD;
- To strengthen the capacity of psychological and health services professionals to provide informed and appropriate sexuality and intimacy training and interventions for people with ASD.

The rights of people with ASD to sexuality and interpersonal relationships are as important, if not more important, than any other basic human rights. Unfortunately their needs in this area often go unmet. Parents must assure that their children with ASD receive the basic information that they need in this area, even though it might be uncomfortable at times. In addition, professionals must step up and get involved by informing themselves and assuring that their training programs are providing adequate experience and information for those in their field charged with the responsibility of helping their clients to learn about their rights to sexuality and close interpersonal relationships and exercising them.

*Professor Gary Mesibov*



Gary is a distinguished psychologist and Professor Emeritus at the University of North Carolina where he spent 35 years on the faculty, the last 19 of which as Director of Division TEACCH- Treatment and Education of Autism and related Communication Handicapped Children. Thousands of staff working with autistic students across the USA and 17 countries worldwide have been trained in the weeklong module that he developed. He also led the development of a comprehensive assessment tool for adolescents and adults in relation to independent living and employment. As well as teaching he was Editor of the Journal of Autism and Developmental Disorders for 10 years, is widely published and received many awards including in 1998 the American Psychological Associations Distinguished Professional Contributions Award for Public Services and in 2010. The Autism Society American Founders Award for Career substantive contributions to the field of Autism Spectrum Disorders. Professor Mesibov continues to lecture and train worldwide.

# 15

## **THE RIGHT of people with autism (and their representatives) to legal representation and assistance and to the full protection of all legal rights.**

All citizens, whether or not they are experiencing any form of disability, should share the same legal rights and expect the same protection from the law. People with autism should not lose those rights because they are unable to represent themselves in a forceful manner. Rather, the protection afforded by the law should be strengthened in recognition of this increased vulnerability.

It is unlikely that people with autism will be able to initiate or sustain legal actions in support of their rights. Under such circumstances, independent legal representation and assistance, should be freely available to individuals or, if appropriate, their carers.

It is necessary for the care and treatment afforded to people with autism to be constantly monitored by an independent agency. This role should not be left entirely to the service provider. Where any deficiencies are observed these should be pointed out by the monitoring agency and appropriate action taken to remedy them. Where further action is appropriate and the person with autism may not be able to adequately pursue his case, an independent advocate, speaking on behalf of the person with autism should be provided.

Legal aid, in terms of finance, should be provided by the appropriate agency when recourse to the courts becomes necessary in the interests of the person with autism.

# Reflections

***Evelyne Friedel***  
***Vice-President Autism-Europe***

It is well known that autism covers a wide spectrum. This means that autism can affect individuals who are severely intellectually impaired as well as those who are above average IQ. Irrespective of their level of disability, all persons with autism must benefit from same rights and these rights must be effectively applied and complied with.

Level of impairment is particularly crucial to be taken into account when legal rights, legal representation and assistance are at stake.

Legal rights, legal representation and assistance are notions to be understood and interpreted in light of Article 12 of the UN Convention on the Rights of Persons with Disabilities.<sup>1</sup>

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## **1 Article 12 of the UN Convention on the Rights of Persons with Disabilities:**

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

Article 12 of the UN Convention requests **equal recognition before the law** for all persons with disabilities and underlines that they have an inalienable right to exercise their **legal capacity on an equal basis with others**.

The UN Convention adds that persons with disabilities who need **assistance in taking decisions shall be provided** with a system of supported decision-making.

The concept of supported decision-making is new to most jurisdictions, and should lead to the reforming of guardianship systems.

### **1 Equal Recognition Before The Law & Legal Capacity**

Pursuant to the notion of “equal recognition before the law”, disabled persons, in particular persons with autism, have their status recognised in the legal order like all citizens. It enables them to hold, exercise and benefit from equal and inalienable rights irrespective of the nature and degree of their disability.

“Legal capacity” is a stronger notion meaning that persons with autism can not only effectively exercise and benefit from their rights but also have the capacity to act.

### **2 Support In Exercising Legal Capacity**

For ensuring the effectiveness of rights and of the exercise of legal capacity, the UN Convention provides that persons with disabilities should enjoy the right to receive support. Indeed, disabled persons, and in particular persons with autism might need support for exercising their legal capacity.

However, **maintaining the full legal capacity of the individuals must always be in the centre** of the process when someone is supporting another person on a decision or is exercising powers of decision-making delegated by this person. Therefore, and in light with the UN Convention, particular due diligence must be applied to act in the best interests of the supported person.

Supported decision-making must always start from the **presumption of full and equal legal capacity** of persons with disabilities, including those with severe and profound levels of disability.

The principle must be the **rejection of the concept of incapacity** and the determination of the degree of assistance must be tailored to the needs and abilities of a person, keeping also in mind that the degree of support can vary from one situation to another for the same person. The assistance or support measures must be proportional to the degree of disability, and respect as much as possible, the right to self-determination.

The role of the support person may vary from providing day-to-day assistance to support in legal representation. The exact tasks totally depend on the wishes and the needs of the person with a disability

High-level support may be needed for some adults with autism, with severe intellectual disabilities who are unable to evaluate the implications and consequences of some of their actions or inactions. Even when high-level support is granted in most or all areas of life including support in decision-making, appropriate measures to be taken by the States must ensure that their legal capacity is nevertheless enjoyed on an equal basis with others.

Regarding persons with autism, the support in exercising legal capacity must not only be based on a personal knowledge of the person but also on the **knowledge of alternative and augmentative communication methods**.

The ability of some persons with severe or profound disabilities to receive, process and send normal communication signals, like e.g. language or gestures, may be very

limited or virtually absent. Some persons with autism use the verbal language in a non-functional way or need communication devices or specific techniques to relay their wishes.

In such contexts, States should recognize that all forms of communication are valid and the way that persons communicate should not be a reason to question their decision-making ability. States should therefore promote model projects and research into how supported decision-making can be implemented for persons with severe disabilities and/or complex needs, such as persons with autism.

### ***3 Selection Of Support Persons & Prevention Of Conflicts***

Support persons should be **selected by the individual or his/her family, whenever possible**. It might be an advantage if they know the individual personally for a significant period of time. In any case, the disabled person should have the possibility to build trust relationships with his/her support person.

There should be the possibility to assign several support persons to one individual, particularly for persons with severe and profound intellectual disabilities where a group of support persons who know the individual in different capacities may better match the support needs of a person.

In no case should support persons be linked to a psychiatric facility, an organisation of service providers or a governmental authority in order to avoid conflict of interests.

In case of conflicts, and to control support persons, administrative procedures that are easily accessible for the supported person and their family should exist or be put in place.

### ***4 Appropriate And Effective Safeguards***

The UN Convention requires that **appropriate and effective safeguards be put in place to prevent exploitation and abuse in the exercise of legal capacity** by persons with disabilities. This is particularly true for persons with autism who need high-level of support in all areas of life and who must always be provided with such safeguards.

The UN Convention adds that the safeguards should be **proportional and tailored to the person's circumstances**. This means that safeguards must be higher for persons with a more severe degree of disability or with high support needs, such as many persons with autism. Safeguards must also be higher in case of major decisions regarding the life of the person.

Safeguards might include in particular a procedure for careful assessment of the actual need for support, periodical re-examination of the measures adopted and possible appeal of decisions by the supported persons or their family. The safeguards must be separate from the support mechanism, since they should protect the person with disabilities from exploitation or abuse by supporters.

In addition, while maintaining their right to take decisions, **persons with disabilities should also be protected from personal harm**. Persons with disabilities may take decisions which are not in their best interest, e.g. giving money to others for

unjustified reason, purchasing goods that the disabled person cannot afford, or resigning from his/her employment.

Support persons have therefore the duty to inform the supported individual by all possible appropriate means about the consequences of any important decision. States should also permit the nullification of contracts in case a person was intentionally exploited or abused.

### ***5 Other Mainstream Mechanisms***

Allowing the nullification of contracts in case a person was exploited or abused means that the supported decision-making system is not the sole measure to be put in place to protect the persons with disabilities.

**Mainstream mechanisms** such as in particular consumer protection and information, rights of medical patients, rights of employees, **should be made more accessible and inclusive.**

States should indeed ensure that these existing legal mechanisms for protecting citizens' rights in different areas of life are accessible to persons with disabilities, accommodate their needs and take their interests into account.

*Evelyne Friedel*  
*Vice-President Autism-Europe*



Evelyne Friedel was president of Autism-Europe from January 2008 until December 2011. In January 2012, she became vice-president of the international organisation. Evelyne Friedel is the mother of a 16 years old autistic boy and defends, with Autism Europe and other French organisations, the fundamental rights of autistic people before the national & European authorities.

Evelyne Friedel is also Doctor in law and attorney, member of the Paris Bar. She graduated from the universities of Paris and Georgetown (Washington D.C.). Evelyne Friedel is partner of the international law firm Taylor Wessing, and practices in European law.

In 2002, on behalf of Autism-Europe, Evelyne Friedel has lodged a collective complaint before the European Committee of Social Rights of the Council of Europe. This collective complaint denounced the non compliance by France of its international commitments taken on account of the European Social Charter. In November 2003 and March 2004, the European Committee of Social Rights and the Committee of Ministers of the Council of Europe rendered their decision stating that France has failed to fulfil its educational obligations to persons with autism under the European Social Charter.

Since 2004, Evelyne Friedel has continued acting both at the European and at the national level in favour of the fundamental rights, and in particular in favour of the fundamental right for education of people with autism and of people with complex dependency needs.

# 16

## **THE RIGHT of people with autism to freedom from fear or threat of unwarranted incarceration in psychiatric hospitals or any other restrictive institution.**

In a civilised country, removal from society would be reserved for those people who have been judged guilty, in a court of law, of a serious criminal offence. The isolation from society of people with autism who have committed no such offence is inappropriate and unjustifiable. The routine incarceration of such people is evil and a severe indictment of any country where the practice continues.

It is recognised that there could exist a very small group of people with autism whose behaviour is still so difficult that psychiatric intervention is appropriate. Such intervention should only be considered when it is proven beyond doubt that the person with autism presents an actual and severe threat to him or herself or other members of society.

Where, as a last resort, a psychiatric hospital is deemed appropriate, the service must offer genuine educative and training programmes which are subject to all the principles described in this charter. Progress should be monitored and the situation reviewed constantly to ensure rehabilitation into a less restrictive environment at the first possible opportunity.



# Reflections

***Rutger Jan Van der Gaag***

***Professor of (Child & Adolescent) Psychiatry, at the University Medical Centre  
St. Radboud in Nijmegen (the Netherlands) and President of the Netherlands  
Psychiatric Association.***

## ***Autism an Invisible Handicap***

***A source of unfortunate confusing situations in psychiatry!  
that are intolerable!***

Autism is an invisible handicap. By far the biggest handicap for people with characteristics as seen within the scope of the development known as Autism spectrum Disorders (ASD), is that their handicap at first glance is not perceived as such by lay people and many professionals. Moreover many people, including professionals in the field of (Mental) Health and Social Services have insufficient knowledge on the variety of clinical presentations of ASD. Often they are misled by the one or two cases they know and tend to want to generalize them. Moreover many professionals have stereotype prejudices on ASD and tend to think every person with ASD looks like Rainman.

When it comes to diagnosing ASD in people that suffer impairment in interpersonal, professional and social functioning, many professionals in psychiatry and psychology tend to confuse diagnosis and classification. Whereas diagnosis, literally meaning “knowing thoroughly the individual case” that is having made a comprehensive assessment to ascertain the strengths and weaknesses of the individual case, thus knowing how this person may react in certain circumstances. The classification relates to what all cases have in common and is per se a simplification. In the practice of the current classification systems it reduces ASD to a triad or even a set of two core symptoms: impaired development of reciprocal social relations and a restricted and rigid pattern of behaviours. How does one then understand the anxieties, obsessions, hyper- or hyposensitivities, bouts of anger and rage that may have such an impact on their daily lives. These emotional and behavioural consequences of ASD are, unfortunately, often misinterpreted by clinicians unfamiliar with autism and the behavioural consequences of their “different” way of perceiving, understanding and reacting to their surrounding world.

A sad story: in our country people with ASD can obtain a so called “Auti-Pass”. It is a plastic document as big as a credit card showing on one side the personalia of the persons and on the other some explanation on general reaction types as encountered in people with autism. The Netherlands Autistic Society created the pass after a very unfortunate drama!

*On a sunny Saturday afternoon, Jonathan a young adult was plane spotting along the fences near the runway at Schiphol Airport near Amsterdam. Where most plane spotters tend to cluster together and share experiences and like to exchange, this person preferred to stay aside and moved away from anybody coming anywhere near to him. A police patrol found his behaviour somewhat suspicious and approached him calmly. He avoided speaking to them and ran away. This stirred*

*their suspicions and when they got near to him he became furious and very aggressive. When they managed to arrest him, he was in such a state of confusion that they asked for a consultant psychiatrist, who had him admitted “on basis of an acute aggressive state of psychotic confusion” with a mental health act. Once on the ward, he was so utterly confused and anxious that he did not manage to give a correct name, nor address so they could get in touch with his family. Luckily his parents were concerned when they got the message from his sheltered home buddy, that he had not returned from plane spotting. They called the police and went to the psychiatric hospital straight away. There they explained that their son had autism and that he could sometimes become rather violent when approached too directly. His aggression was merely a reaction to his inner state of panic. They explained how to approach him cautiously, by not facing him but taking a parallel position, sitting next to him at a certain distance and speaking to him calmly and slowly. This attitude worked perfectly and within minutes he calmed down and was able to explain coherently that he was plane spotting but because of his autism was afraid to be approached by strangers. The mental act was lifted and he was allowed to leave the hospital straight away with his parents.*

Jonathan was fortunate. If his parents had not been able to come along quickly and explain to the psychiatrists and nurses who their son is and what was happening to their son, he might have been secluded and “incarcerated” for a much longer period of time in a service that was not at all suited to be helpful to him, because the basis knowledge of who he is, what is autism may bring along, and even more importantly how he should be approached and treated, was absolutely lacking! The Anti-pass may prove useful in these difficult situations.

But in our country and throughout the world not all persons with autism are as lucky as Jonathan was in his situation.

It is obvious some people with autism may present with a psychosis or catatonia or an affective state (mania – depression) that may necessitate intensive psychiatric treatment and sometimes temporary restrictive measures or temporary warranted incarceration under a mental health act. But in those cases it is of utmost importance to ensure that the staff on that department is aware of the underlying autism and well instructed by family or other care providers about the specific ways of communicating with the individual with ASD. In all other cases people with ASD may be held far longer than necessary in psychiatric services due to a lack of understanding of their specificities or differences.

Autism should be included in the curriculum of all involved in the care for acute psychiatric distress: general practitioners, police and social workers, doctors and nurses in emergency wards and all involved in psychiatric care from infancy to old age! Knowing and understanding autism may prevent unnecessary vicious spirals of anxiety – aggression – restriction – panic etc!

Patients have the right to be treated and helped by knowledgeable professionals. And should the professionals not be competent they should immediately ask for consultation to improve their competences and skills in dealing with patients with autism and their parents (regardless of their age!).

*Rutger Jan Van der Gaag*



Rutger Jan van der Gaag is professor of psychiatry (child & adolescent) at the University Medical Centre St. Radboud and Karakter University Centre for Child & Adolescent psychiatry in Nijmegen the Netherlands. As director of training he is involved in the guidance of young professionals. His research over the past thirty years has focused on developmental psychopathology (autism, ADHD, addiction etc) and is characterized by a broad scope from epidemiology and clinical trials to neuroimaging and psychophysiology as reflected in over a hundred (international) publications.

He is an advisor to many Autism Societies in Europe and around the world. He has been on the scientific board of AutismEurope for the past fifteen years. He is a columnist in Engagement the magazine of the NVA (Dutch Autism Society) in which he writes mainly on the impact of autism for the individual and family environment.

His professional and political involvement in matters of mental health and stigmatization is also reflected by his appointment since 2008 as president of the Netherlands Psychiatric Association

# 17

## **THE RIGHT of people with autism to freedom from abusive physical treatment or neglect.**

Any therapy used in the treatment of people with autism must be potentially beneficial to the individual with autism. Methods which depend upon any form of punishment for inappropriate behaviour are not acceptable in society at large or when applied to people with autism or any other form of disability.

In particular, no treatment which results in any of the following is acceptable:

1. Evidence of physical pain or discomfort;
2. Potential or actual physical effects such as tissue damage, physical illness or stress;
3. Verbal abuse or insult directed at the person with autism;
4. Threats or intimations of future actions which cause fear or anxiety to the person with autism;
5. Denial of food, warmth, basic hygiene, or other necessities of life;
6. Exposure to humiliation, discrimination or degradation;
7. Neglect.

Where such practices occur, they should cease. If such actions are serious or if they are continued after their unacceptability has been established those responsible should be disciplined according to local custom and law.

# Reflections

**Gary W. LaVigna**

For those people who have the challenges typically associated with Autism Spectrum Disorder (ASD), one of those challenges is often their behaviour. This gives them the need for and the right to the least restrictive support capable of meeting their needs and the needs of their family and those around them. Unfortunately, because of their challenging behaviour, they often experience abusive physical treatment or neglect.

An example of the physical abuse that those on the spectrum can experience comes from an actual case. The behaviour of concern was self-injury, which included striking his head or nose with his fist or against another object. Before being referred for an assessment and a plan of support, he had been treated in another setting. In that treatment setting, the behaviours were initially addressed through aversive consequences, including bare-bottomed smacks, water squirts, pinches, and the like. Over time, the consequences only escalated the problem. As a result, after more than a year of such treatment, on one day alone he received 177 bare-bottomed smacks. (This agency still provides services, but has moved from using bare-bottomed smacks to using contingent shock.) The Positive Behaviour Support (PBS) plan developed for this boy did not involve any punishment, let alone any abusive physical treatment. In this “Charter of Rights for People with Autism”, I will describe how challenging behaviour can be addressed effectively, using PBS, without abusive physical treatment.

## ***Positive Behaviour Support (PBS)***

### ***Outcomes***

Based in non-linear Applied Behaviour Analysis, PBS start with a clear statement of the desired outcomes of treatment. In addition to eliminating the use of any restrictive procedures, including abusive physical treatment, these include:

1. A good quality of life, including community presence and participation in ways that are age appropriate and valued by society; choice and autonomy typical of ones chronological age; increasing independence and productivity; social relationships and friendships; and full engagement in a lifelong process of learning, growth and development;
2. The removal of those behavioural barriers that may get in the way of these quality of life outcomes, including reducing and if possible eliminating the occurrence of these behaviours, as well as reducing their level of severity when they do occur;
3. A lasting extension of these outcomes to all settings and situations;
4. All being accomplished with minimum, if any, negative side-effects;
5. With the outcomes and support being with the full consent and agreement of the person and their family.

## ***Assessment***

The first step in developing a PBS plan is to carry out what is called a functional assessment. What most people refer to as challenging behaviour virtually always serves a legitimate function for that person. Therefore, the purpose of a functional assessment is to understand the meaning of the behaviour from the person's point of view. The process involves gathering all the information and putting it together so a clear understanding emerges. This is not unlike gathering all the pieces of a complex jigsaw puzzle and putting those pieces together in a particular way so the picture emerges and can be understood. Since one does not know what the critical pieces are before hand, all the available information must be gathered. Following is some of the information that goes into a comprehensive functional assessment:

### ***A. Referral Information***

### ***B. Description Of The Person***

1. **Physical Characteristics**
2. **Cognitive Abilities**
3. **Communication Abilities**
4. **Motor/Perceptual Abilities**
5. **Self-Care Skills**
6. **Social Skills**
7. **Community Skills**
8. **Domestic Skills**
9. **Leisure/Recreation Skills**

### ***C. Other Background Information***

1. **Family History and Background**
2. **Living Arrangement**
3. **Program Placement**
4. **Health and Medical Issues**
5. **Service History**

### ***D. Mediator Analysis***

### ***E. Motivational Analysis***

### ***F. Functional Analysis of Behaviour***

1. **Description of Problems**
2. **History of Problems**
3. **Antecedent Analysis**
4. **Consequence Analysis**
5. **Ecological Analysis**
6. **Impressions and Analysis of Meaning**

### ***Support***

Based on a comprehensive functional assessment, to achieve the broad range of desired outcomes described above, multi-element, positive behaviour support (PBS) plans are needed. Such plans include Ecological Strategies aimed at removing the mismatches that were found between the focus person's needs and characteristics and their physical, interpersonal and service environments (such as by providing a 15-minute by 15-minute visual daily schedule; by increasing the density of preferred events in the person's life; and by increasing the amount of choice and control the person has); Positive Programming designed to teach a variety of general skills (for example, being able to independently use a CD player to listen to music), functionally equivalent skills (for example, how to ask for help when they need it), functionally related skills (for example, how to discriminate between appropriate and inappropriate options among those that have been made available), and coping and tolerance skills (for example, how to tolerate performing an important but non-preferred activity); Focused Support strategies designed to achieve rapid control over the behaviour and to reduce the need for reactive strategies, such as antecedent control (i.e. avoiding those events associated with the higher likelihood of the behaviour and introducing those associated with the lower likelihood) and certain schedules of reinforcement (for example, differentially reinforcing the absence of the undesired behaviour for a specified period of time); and Reactive Strategies designed to get rapid, safe control over the situation without resorting to abusive or restrictive physical intervention. PBS that includes all of the above elements is often referred to as "multi-element."

### ***Implementation***

Regardless of the quality of a PBS plan, lack of consistent implementation can still reflect neglect and result in abusive physical treatment. The principles and procedures of organizational behaviour management should be used to assure consistent implementation. These principles and procedures include specifying in detail exactly what needs to be done, frequent monitoring to determine what is being done and what is not being done, frequent feedback, including visual, to those who are responsible for implementation, and training to assure that those responsible know how to do what they are responsible for doing. This process includes the writing of detailed procedural protocols for each component of the plan, fidelity checks to assure that once trained, those responsible don't inadvertently drift away from the written plan, and ongoing data collection to assure that all of the established objectives are being met. Checks should be carried out regularly to assure the reliability of the data that are being collected.

### ***Duty of Care***

People who face the challenges associated with autism, including the control of behaviours which may put them and/or others at risk, have the well established right to effective treatment. To deny them this right amounts to neglect. In recognition of this, many services, service agencies, governing boards, professional associations and funding sources have established "duty of care" policies and procedures. Some of these prescribed policies and procedures specifically address intervention when a behaviour represents an immediate risk of harm or injury, such as self-injurious behaviour and physical aggression toward others. Unfortunately, "duty of care"

policies and procedures themselves, often lead to abusive physical treatment. This abuse can be a result of what can be called the “fallacy of alignment.”

### ***The Fallacy of Alignment***

Certainly, there would be agreement that if a person challenged with autism were engaging in harmful self-injurious or physically aggressive behaviour, those involved would have the responsibility to physically intervene if this were necessary to prevent serious injury from occurring. **(Note: There is no basis in the provision of ethical treatment for the use of any procedures that produce pain or humiliation or deprive the individual of basic needs.)** Based on this, most treatment settings have adopted a particular system of physical management if necessary **as a last resort**. The way such treatment plans read, if precursor or less serious behaviours occur that may lead to behaviours that could lead to harm, more benign strategies, such as redirection or distraction, should be used. However, if the immediately threatening behaviour occurs, physical management may be necessary, again, **as a last resort**. This can lead to the “fallacy of alignment” which would be that if the immediately threatening occurs, physical management is necessary “**as a first resort**” because of “duty of care.”

### ***The Role of a Reactive Strategy***

There are two reasons for minimizing the use of physical management strategies. The first is that, if it is used unnecessarily, it is abusive. The second is that it may produce the opposite effect than the one required of a reactive strategy. As described above, the role of a reactive strategy in a multi-element PBS plan is to get rapid, safe control over the situation. Attempts to physically manage a behaviour can often produce the opposite of this effect, that is, it can often escalate the behaviour to a higher level of episodic severity. There are quite a number of reactive strategies that can be included in a PBS plan that can preclude the need for physical management, even if the behaviour is actually resulting in injury. Which reactive strategies are included in a plan would be based on the results of the comprehensive functional assessment based on expected effectiveness in getting rapid, safe control, but could include one or more of the following:

1. Ignore
2. Redirection
3. Feedback
4. Guided Instruction
5. Active Listening
6. Stimulus Change
7. Inter-positioning
8. Counter-intuitive

### ***Counter-intuitive Strategies***

Counter-intuitive strategies are a good example of how the need for physical management can be avoided. “Counterintuitive” is used to label this particular category of reactive strategies, since, while they do seem likely to result in rapid safe



control, they would appear to have the potential to reinforce the behaviour, making that behaviour more likely to occur in the future (clearly, an undesired effect on challenging behaviour). Among others, counter-intuitive strategies include redirecting the person to a preferred activity or event or to the opportunity to engage in a obsessive/compulsive behaviour.

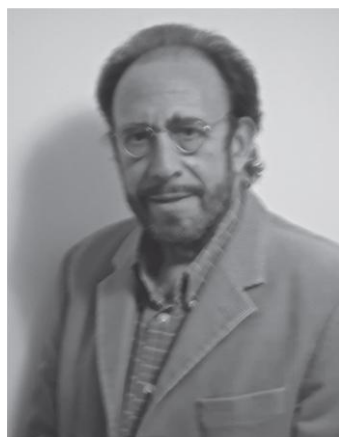
For example, in once case as part of a PBS plan, a professional had recommended physical management, out of a “duty of care” responsibility, in which, if the focus person actually became physically aggressive toward staff, four staff would physically establish control over him to stop this behaviour and place him in a locked room until he had calmed down. Initially, he could not conceive of a better strategy. However, in exploring the information included in the comprehensive functional assessment, it was known that he obsessed over helicopters. If there was a helicopter flying overhead, he would not move or do anything other than look at it until it was out of sight. It certainly wasn’t going to be practical to keep a helicopter on the property, ready to fire up and lift off as a reactive strategy. However, not surprisingly, if a TV episode of MASH came on, he obsessed over that until the opening sequence was over. People familiar with MASH may recall that its opening sequence is centered on a helicopter coming in and landing on a hill. Suggested reactive strategy: ...keep an episode of MASH cued up on the DVD player and if physical aggression occurs, use a remote switch to play the MASH episode; the result: physical aggression stops and he is focused on the TV.

Based on the principles of non-linear applied behaviour analysis, different elements of the PBS plan prevent reinforcement of the physical aggression from occurring. These, of course, would include other non-contingent access to MASH and helicopters, beyond its use as a reactive strategy.

### ***Conclusion***

People who face life with the challenges associated with autism have the right to the least restrictive, effective treatment. Multi-element PBS provides this. While physical management may be necessary to prevent harm or injury, it should be used literally as a last resort while avoiding the fallacy of alignment. Reactive strategies should be evaluated by their measured effectiveness in producing rapid safe control and should include counterintuitive strategies. There are no circumstances under which strategies which produce pain or humiliation or deprive the individual of basic needs are needed or justified.

Gary W. LaVigna, Ph.D., BCBA-D



Gary LaVigna is Clinical Director and Co-founder (with Tom Willis) of the Institute for Applied Behavior Analysis (IABA) in Los Angeles, California <[www.iaba.com](http://www.iaba.com)>. He spends much of his time consulting with families and organizations on establishing positive behavior support plans for individuals exhibiting severe and challenging behavior and presenting seminars and practicum training on the topic throughout the world. His work is reported in numerous published articles and his co-authored books - *Alternatives to Punishment*, *Progress Without Punishment* and *The Periodic Service Review: A Total Quality Assurance System For Human Services and Education*. As a part of training thousands of people from around the world, he has had a professional presence on every continent, with the exception of the Antarctic.

Established in 1981, IABA now has a staff of approximately 600 people providing a variety of direct services beyond training and consultation. In 1985, IABA initiated one of the first supported employment services in California for people who courageously face life with an intellectual and/or developmental disability associated with challenging behavior. (It is this population that IABA is organized to serve.) It is notable that their individual earnings over the years have added to a running total of what is now more than \$8,000,000. In 1989, IABA again made California history by initiating its first supported living services. Finally, IABA provides a range of “youth” services, namely inhome respite for families, intensive support so children can continue living with their families and go to neighborhood schools, and early intervention for young children diagnosed as having the characteristics associated with autism.

# 18

## **THE RIGHT of people with autism to freedom from pharmacological abuse or misuse.**

Medication should be used sparingly and only when absolutely necessary. Wherever possible, the medical practitioner should be able to discuss, with carers, the possibility of using strategies other than those using drugs to overcome the particular problems. Medication can never be acceptable as a substitute for adequate care.

People with autism have a right to medication only when it is for their own benefit and in their own interests. No medication should be provided when this is merely for the convenience and ease of those caring for them. No medication, apart from that which is freely available to the general public, should be administered except under the direct control of a qualified and competent registered medical practitioner.

No effective medication is free of side-effects and the prescriber must be confident of a therapeutic advantage in any prescription. Where there is a likelihood of significant side effects, the individual must be monitored for their occurrence. Those immediately in contact with the person must be warned and alerted to any potential side-effects and these should be reported immediately to the prescriber for his or her consideration. People with autism do not always respond as expected to drugs so any abnormal effects must be reported to the prescriber.

All medication must be of the quality and standard normally accepted in that country. Medication must be given to the patient in the form specified and must be given at the specified dosage, conditions and time intervals. Prescribers should take steps to determine circulating blood levels where appropriate and possible.

The individual's response must be monitored on a formal basis. Any ineffective medication must be stopped. Where sideeffects become apparent steps should be taken to minimise them. Individuals should be monitored for the early signs of the appearance of long-term effects such as dyskinesias. Medication should, in any case, be reviewed regularly and wherever possible minimised or replaced by substitutes which may be safer or more effective.

Except for short periods of time and in particular circumstances, the use of major tranquillisers cannot be justified. Certain atypical tranquillisers, used at low dosages, may be appropriate for certain individuals on a longer term basis. Generally the use of tranquillisers does nothing to help the person with autism but serves only to sedate the afflicted person and to make him or her more manageable. At the same time such drugs will impair learning and decrease the happiness and understanding of the individual. Long term effects, including the occurrence of tardive dyskinesias are irreversible.

Funding should be available, from the responsible agency, to pay for appropriate medication.

# Reflections

*Paul Shattock*

## ***Introduction***

We all experience problems (pain, disease or psychological) which can be controlled or ameliorated by the use of medications at some time in our lives. To deny such intervention would be considered as inappropriate. It is a fundamental right of people with autism spectrum conditions (ASCs) to receive such treatment if it is in their interests (See Right 9).

Physicians and others who prescribe medications are doing so to improve the quality of life, as they see it, of the individual. However, the range of available options is limited. Sadly, the ultimate choice is often affected by other considerations. So while the cost to parents or others paying for the medication would not, in an ideal world, be relevant, it is an important consideration for prescribers in most of the world. Newer drugs tend to be costly but may offer distinct advantages. Such advantages can sometimes be the product of the manufacturers' imaginations and newer problems may become apparent with time and experience.

## ***Preliminary Considerations***

The most blatant form of abuse is the practice of using medications to make a person less difficult to control. The behaviour and compliance of "patients" and, therefore, their ease of handling, can be dramatically modified by medications. A few years ago, such practices were largely routine and the side-effects of medications made life intolerable for many people with ASCs. There were numerous, hideous instances where the long term administration of medications resulted in severe and permanent damage to individuals and could include their death. The appearance of such symptoms was regarded as an inevitable consequence of the condition itself. These long term effects were not, at that time, understood and the only drugs available were crude in terms of side effects and predictability. This is no longer true and the administration of such "chemical cosh" medication regimes is no longer acceptable. (It must however be accepted that there exist isolated instances where other drugs have failed and such discredited medications do show unexpected benefits and are justified.)

Nowadays, most drugs have fewer side-effects and these effects can be monitored and largely, but not always totally, avoided. Drugs are essentially toxins in that they affect bodily functioning. These effects can be exploited to advantage in certain situations. Sadly, the expertise is not always available to monitor such situations and the funding not available to provide any but the cheapest and less specific medications. The prevalence of unpleasant side effects will, almost inevitably, be increased.

There are currently no medicines which are designed to ameliorate the core symptom of autism. There are many medicines which, if used correctly, can ameliorate some autistic symptoms and other comorbid symptoms which are frequently associated with autism.

## ***Diagnosis***

Appropriate medical treatment depends upon an accurate diagnosis and a thorough assessment of any underlying or superficial problems. The diagnosis of people with autism, especially adults, is difficult and incorrect diagnoses are still commonplace. One particular problem occurs with the confusion of autism and schizophrenia. Some medications given to people with an ASC are completely and utterly inappropriate and result in worsening of the symptoms. The medication is deemed to be ineffective at the dosages suggested and this is increased further. Inappropriate medication resulting from incorrect diagnoses represents serious abuse.

## ***The Choice of Medications for “Autism”***

Individuals labeled as “autistic” are very different from each other. The differences between them are much greater than they are within the so called “neuro-typical” population. One man’s meat is very definitely another man’s poison. A particular medication can be very helpful and well tolerated by one person but unhelpful and very harmful for another. Some people with autism benefit dramatically from drugs known as SSRIs (selective serotonin reuptake inhibitors) that are commonly used for treating depression (provided the dose is correct). For others, especially those with more severe problems, the results can be disastrous. A statement in a book or research paper that a particular drug is useful for people with autism does not guarantee success with any particular individual. The use of any medication, as with any form of intervention, must be seen as a time limited experiment. If it works and side effects are limited – continue with caution. If it does not help and/or produces unpleasant side-effects ..... stop and reconsider. Consider the actual drug. Are there alternatives? Consider the dose. Are we using enough or too much? Are there side- effects or interactions that are affecting the quality of life of the individual?

Carers should be aware of potential side-effects and constantly check for them. It is not always possible, for example, for the prescribing physician or consultant to do this personally so carers must be trained and sensitized to them. For example, some drugs cause an inflammatory response in the intestines. It is impossible for some people to tell us of this pain but we can surely be aware that the drinking of copious amounts of water could indicate heartburn or intestinal irritation. Such behaviour is not of “psychological” origin and should not be treated by, for example, behavioural therapy. Such responses are logical attempts to lessen pain by intelligent people and should result in our addressing the underlying, medical or other, condition.

## ***Spotting Adverse Reactions***

Whenever there is a change in behaviour or appearance of a rash or other physiological response (such as diarrhoea) the first response should be to “think drug”. Has the medication regime been changed? Has the dose been changed? Has anything else been changed that could possibly result in such an effect? One should be aware that many drugs interact with each other. More often than not, there could be a cumulative effect. One plus one does not necessarily equal two. It could be three or four or one where drugs are concerned.

I cite a specific example of a man of 40. He had been taking a medication (carbamazepine) for about 20 years. This is an excellent drug to treat epilepsy but, in his case, it was initially administered to reduce behavioural problems. He had also,

for a similar length of time been taking the antipsychotic drug risperidone. It was decided to remove the carbamazepine and this transition appeared to be accomplished without problems. Two months later, it was observed that the man was showing pronounced side-effects which are typical of risperidone. It was found necessary to reduce the dosage of risperidone considerably (but gradually). It is now known that the anti-epileptic drug induces the formation of the enzyme which breaks itself down in the body. By chance, this same enzyme also breaks down risperidone. As soon as the carbamazepine was removed, the circulating levels of the risperidone increased dramatically and he was, effectively, overdosing on the drug. These very serious interactions were not known at the time he was first prescribed them. They also appeared gradually rather than all at once and so were less obvious to those supporting him. Checks on medication, side-effects and potential interactions should be a regular feature of care. Most dispensing Pharmacies have computerized systems which warn of such effects at the time of dispensing. Checking with the Pharmacy is simple and without cost. In this particular instance, the problem was resolved by reducing the risperidone dose incrementally over a few months.

No two people, whether or not they are affected by autism, respond identically to all medications. It is nowadays universally acknowledged that some biochemical or metabolic processes function in a different way in people with ASCs. Why, therefore, should we expect that those diagnosed with autism will react to medications as people with other conditions or with no clinical conditions at all? For example, barbiturates were mainly employed as sleeping pills but for people with autism they had the reverse effect. They acted as stimulants. Amphetamines are frequently used to keep people awake and active for long periods of time but for people with ADHD – attention deficit hyperactivity disorder - (a common comorbid condition to autism) they are often helpful for ameliorating problems of hyperactivity and lack of concentration. Such paradoxical effects mean that people with ASCs will often not respond in the way the textbooks suggest they should. In such cases, the textbooks are wrong and the person responsible for medication should be guided by what they actually observe with the patient.

### ***Observations on the use of Biomedical Interventions***

Although not universally accepted within the medical profession, there is a substantial body of research which indicates that some systems required to metabolise (break down) drugs are less efficient in people with ASCs. The consequence is that many drugs persist in the body for longer periods than is normal and the doses required for people with ASCs are, as a consequence, often very much lower than those for people with other conditions or no conditions at all. When introducing medication, the prescriber should be careful to start at a dose which is lower than would normally be used and gradually increasing it until an optimal effect is observed. Medical practitioners nowadays are much better at recognizing this issue than in former times although there are still some very distressing cases where physicians insist on giving what are effectively overdoses of medications and these exacerbate the problems and introduce new ones. Sadly, the legal systems around the world still fail to address these issues adequately.

One must also bear in mind that interventions designed to boost the normal metabolic processes could, conceivably, result in an increased rate of breakdown of

medications and increased levels could be required. I will cite one such possibility. The situation is purely hypothetical and I have never heard of this particular response in practice. However, most practitioners familiar with complementary practice will be aware of such an eventuality. It is generally accepted that people with an ASC exhibit deficiencies in their ability to sulphate some drugs. This “sulphation” represents the first stage in the breakdown and removal of the drug from the body. Paracetamol (or acetaminophen) is the classic example and its increased persistence in the body of people with ASCs was demonstrated over 20 years ago. Many other drugs are broken down using similar systems. Many people with ASCs and many other conditions attempt to supplement their circulating sulphate levels by adding Epsom Salts (Magnesium Sulphate) to bathwater or using the food supplement MSM (Methyl-Sulphonyl-Methane) orally. Supplementation to enhance sulphating ability could, therefore, result in an increase in breakdown of medications such as some anti-epileptics and it may be necessary to modify the dose accordingly. The net effect would be that putting Epsom Salts in the bathwater could appear to stimulate a seizure.

It is essential that those parents and carers making use of such supplements (including all vitamins and minerals) should inform their prescribing physicians so that appropriate consideration can be given. Sadly, many physicians dismiss all such “biomedical” approaches as delusional at best. I am aware of some parents who dare not tell their own physicians that they are utilizing such interventions.

It is a fact that too many physicians exhibit a very strong antipathy towards all medical treatments which do not employ drugs produced by large pharmaceutical concerns. At the same time there are parents and people with ASCs themselves who will not tolerate any synthetic medication but will happily use anything described as “natural” especially if reinforced by a picture of a thatched cottage and a cow on the box! This mistrust of prescription medications is often the consequence of previous unpleasant experiences with prescription medications.

My personal opinion is that attitudes are changing but far too slowly for the good of “patients”. Supportive evidence for the effectiveness of some interventions, described as complementary, is appearing and most physicians are, at least, tolerating experimentation by parents. It is disappointing that the regulatory agencies throughout the world adopt such a discouraging and confrontational approach to those interested in offering such support.

The problem seems to be particularly polarized in those countries where there is a pharmaceutical industry and where there is considerable financial support from state or insurance based schemes. It is frequently cheaper, for the consumer, to use prescription medications rather than nutritional supplementation or exclusion diets.

### ***Correct Administration of Medicines***

Once the medication regime is agreed, the actual administration to the subject is often (usually) imperfect to such an extent that many of the intended benefits are diminished or completely lost. Other harmful effects may appear. The timing of the administration and spacing through the day; the instructions to take with or before meals; the requirement to give at least 100ml of water with a medicine must be

respected. Some capsules can, when given dry, adhere to the side of the oesophagus and release their contents there so causing inflammation, ulceration and pain. Such effects can easily result in the refusal of medication by persons with ASCs.

### ***Concluding Comments***

The use of medication is but one part of a specific programme for a particular individual at a particular time. The drug without potential side-effects does not exist. Medication should be regularly monitored for effectiveness and known or predictable side-effects and interactions with other interventions. Staff responsible for the care of individuals should be trained to identify reactions to medication on behalf of the subject especially if they lack language. Alterations to doses will often suffice to ameliorate such adverse reactions but it may be necessary to change the medication regime.

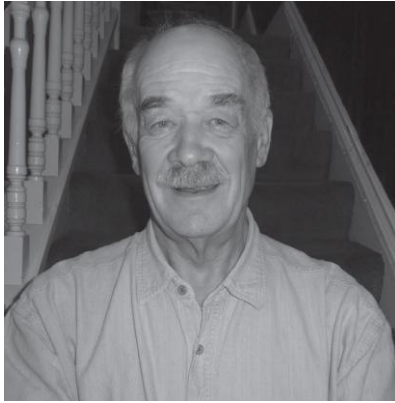
Treatment of people with ASCs is extremely difficult and there are very few, if any, treatments that guarantee success. The use of medical interventions can, if used appropriately, result in much improvement in the quality of life for the individual and, in consequence, to the family and carers. The welfare and happiness of the person with autism is paramount.

Throughout this presentation, I have used the word “*Condition*” rather than the current, medically definitive term “*Disorder*” in order to describe the status more accurately. This is becoming standard practice in the UK. The change reflects the developing understanding that the autistic spectrum represents a part of the full tapestry of humanity rather than a variation that is unnatural, wrong or deviant. Thus Autism Spectrum Disorder (ASD) is nowadays described as an ASC.

*(This chapter contains only the outline and certain basic elements of the problem and how we can best use medical interventions. For a fuller discussion, visit the WAO website at [www.worldautismorganisation.org](http://www.worldautismorganisation.org) )*



*Paul Shattock*



**Paul Shattock:** Parent of man (born 1970) with classic autism. Senior Lecturer in Pharmacy and related subjects at University of Sunderland 1966-96. Honorary Secretary of Tyne and Wear Autistic Society (Now North East Autism Society) 1975-88; now Honorary Vice President. Founding Chairman (1989) of ESPA (Education and Services for People with Autism) providing residential and day services for over 200 adolescents and adults with ASCs in North East England. UK representative and Honorary Secretary of Autism-Europe 1990-2000. Member of Council and Executive Committee of National Autistic Society 1980-2000; now an Honorary Vice President; Currently President of World Autism Organisation. Founder of Autism Research Unit (now ESPA-Research) in 1982. Appointed Officer of the Order of the British Empire (OBE), by the Queen, in 1999.

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## **THE RIGHT of access of people with autism and their representatives to all information contained in their personal, medical, psychological, psychiatric and educational records.**

Although the extent of availability may vary, it is a legal requirement in many countries that people should have the right of access to all information about themselves which is stored on official records. It is unacceptable that such information is available for others to read but not to the person most affected or, in the case of many people with autism, their representatives.

Many instances have occurred where inaccuracies caused by ignorance, misunderstanding, prejudice or malice, have appeared in official records. Such inaccuracies can endure permanently unless challenged and corrected; inappropriate or unfair treatment may occur as a consequence. Official records should, wherever possible, be agreed by the agency and the person or their representative before becoming part of any official record.

The care and treatment of people with autism relies upon a partnership between many agencies. Such a partnership can only be successful when all participants, including those most affected, work together towards common objectives and based upon the same information.

The personal information stored in such records should not be made available to outside agencies, including researchers, without the express permission of the person with autism or, if this is impossible, their representative.

## Reflections

***Stephen Shore Ed.D.***

“No, I don’t think we are looking at mental retardation” the pediatrician informed my worried parents as he considered why their third child had lost verbal communication skills a few short months ago at just 18 months of age, was spinning in circles, and having meltdowns. With a concerned and puzzled look on his face, the doctor suggested the possibility of autism and that an evaluation by specialists in this field would be warranted. That toddler was me, the parents mine, as well as was the pediatrician.

Beyond being a sentence for lifetime institutionalization, very little was known about autism and it took my parents months – until I was a toddler of 2 and half before finding a suitable place for evaluation. Professionals had only a fraction of the knowledge about autism that we know today, and although my pediatrician was mystified by my condition, he honorably provided my parents with the best conclusion and recommendation he could give. His providing meaningful access to my medical information to my parents, albeit far from perfect, would have adhered to the Charter for People with Autism that we are fortunate to have today.

The concepts within the Charter for People with Autism follows a tradition of close to 2,500 years as founded in the work of the philosopher Aristotle’s Nicomachean ethics. Contained in this document is familiar pillar of the right to pursue happiness – and its requisite states of fulfillment and productivity – (Hughes, 2001) that forms the basis for a number of constitutions and charters upholding the rights of all individuals. A vital component of effectively pursuing the right of happiness for people both on and off the autism spectrum is having unfettered and meaningful access to one’s own information contained in personal, medical, psychological, psychiatric, educational, and other records maintained by helping professionals. Because contact with helping professionals to meet educational and medical needs for individuals on the autism spectrum tends to be greater in terms of quantity and intensity, having access to this information that is helpful to the person with autism takes on an even greater importance and opens the door to successful advocacy.

### ***Advocacy as a Means for Adhering to the Rights of Individuals with Autism***

“We have never seen a child who is so sick... and we suggest he be taken to a place where people can look after his needs, while you as parents, can attend to the needs of your family” said the leader of the diagnosing team. In shock my mother refuted the call for institutionalization and like so many parents of today, who are encouraged by work such as the Charter for People with Autism, advocated on my behalf *demanding* the James Jackson Putnam Children’s Center in Roxbury, Massachusetts take me on as a client for their services.

My parents accepted me for who I was which should be adhered to as a basic human right. However, at the same time they knew that a lot of work and therapy (now called intervention) was required for me to lead a fulfilling and productive life – another right that all individuals on the autism spectrum should have. As with many

similar situations that are played out by parents of today's children with autism, it took my parents advocating on my behalf to enforce what we now have as a central core of the rights of individuals with autism – access to proper educational and medical resources.

We must remember to be thankful for the work of organizations such as the Irish Society for Autism, the National Autistic Society of England, the Autism Society and Autism Speaks in the United States, The Asperger's Association of New England, Asperger Syndrome and High Functioning Autism Association of New York, Autism Today in Canada, the Autism Self Advocacy Network, and Autism Network International as critical towards reaching the goal of where advocates can act less as guardians and more as facilitators for maintaining the rights of individuals on the autism spectrum.

### ***Implications of the Charter of Human Rights to Meaningful Sharing of Information***

After coming to an agreement for my beginning work at the Center at age four my parents developed what we would today refer to as an intensive home-based early intervention program emphasizing music, movement, sensory integration, narration, and imitation. When their initial attempts to get me to imitate them failed, my parents switched tact and began imitating me. In doing so, I became aware of their existence as they reached into *my* world and established a trusting connection or relationship that is vital to develop before quality education can begin. Techniques for reaching into the world of an individual when necessary to establish a trusting bond should be a mandated part of every educator's toolbox when working with students on the autism spectrum. We need to meet individuals with autism where they are and establish a connection before asking them to come into our world.

Due to the hard work of my parents, by age four verbal interaction skills were beginning to return and I was admitted to the Center that initially recommended institutionalization. Another evaluation upgraded me from Atypical Development, Strong Autism Tendencies, and Psychotic to merely Neurotic. Things were moving up in the world. However, being psychoanalytically oriented, the Center refused to allow teachers to share the day's events in school with the child's parents. A simple parental query as to if their child ate lunch in school was interpreted to have the deep, dark psychological implication of a parent wondering if the school was a better caretaker than they were to their own child. And certainly a mere teacher did not have the psychological insight or background to handle such a weighty question – a mighty restriction of free flow of information!

Today there is much freer sharing of information where sharing of information between educators or medical professionals about a child's situation or progress is a common expectation. The Charter of Rights for people with Autism mandates that we make this back and forth flow of information universal.

### ***Meaningful Sharing of Information for Developing Self-Awareness and Self-Determination***

An important goal in assuring the rights of individuals on the autism spectrum involves developing capacities in self-awareness as a stepping stone to effective

self-advocacy. Success in this effort first requires developing an awareness of one's own characteristics, needs, as an individual on the autism spectrum; which stems in large part from having free and meaningful access to records of oneself.

For example, as early as age 4, my parents noticed me disassembling and successfully putting back together watches in good working order with a sharp kitchen knife. They supported this interest with other objects to take apart and made a big deal about my ability in this area. In this way, they made me as aware of this strength in myself in a manner that was at least equal to what any modern assessment for mechanical aptitude can do today. Armed with this knowledge I was able to seek productivity and fulfillment in my pursuit of happiness in the areas of employment from high school through my bachelor's degree as a bicycle mechanic. Being aware of one's own strengths and challenges is key towards development of a good sense of self-determination as an adult.

By age 6 I entered regular school kindergarten where I was a social and academic catastrophe. Not knowing how to interact with my classmates in ways they could understand and with educators not knowing how to reach me, I was the FLK (Funny Lookin' Kid) in the room. Yet, I'd spend hours gathering all the books of one of my many passions at that time and read them – over and over – sometimes wondering if there was more to school than sitting all day studying these books. Should I be doing math or reading in groups, for example? One day while I had a stack of astronomy books on my desk a teacher told me that I'd never learn how to do maths. However, somehow, I managed to pick up enough on the subject to teach statistics at the university level.

While educational and social difficulties remained constant in elementary school, I still learned material at a different and often unique way. I believe large part of my success was that my parents freely shared information about my being on the autism spectrum in a way that was meaningful to me. Since about age 5 and a half, after my speech had mostly "normalized" I was aware that I had this "thing" called autism. We still didn't know much about it. However, my knowing that I was on the autism spectrum helped greatly in understanding my differences.

The process of disclosure to an individual that they have autism begins when it is known they have a diagnosis, and can be discussed in a developmentally appropriate manner at any age. It may not be necessary to use the label "autism" to a toddler. However, conversations about strengths, challenges, differences, and nonjudgmental comparison of characteristics with others can be started at anytime "teachable moments" occur, with the end goal of the individual learning about their label becomes the last piece of a mosaic of understanding; rather than the term being a puzzle of shame and confusion (Shore, 2004).

### ***Moving towards Effective Self-Advocacy***

The second step to educating individuals on the autism spectrum to implementing the Charter of Rights for People with Autism includes learning successful skills in self-advocacy. In addition to have a full sense of how being on the autism spectrum affects them in their life, the successful self-advocate has been educated in scanning the environment for challenges specific to them, advocating for their needs in a way

others can understand and provide support, and disclosing the reason why an accommodation or greater understanding of one's situation is needed (Paradiz, 2009; Shore, 2004).

Schools are charged with educating the nation's youth to productive citizens. In keeping with the Charter of Rights for People with Autism, part of that education should involve teaching the skills of effective self-advocacy.

### ***Conclusion***

In summary, we have come far from those early days of an autism diagnosis as tantamount to a wasted life in an institution to this new era of individuals on the autism spectrum being appreciated for who they are rather than how much they are like the general population. This development is in part due to the increase of initial awareness of autism as part of the human condition resulting in greater advocacy efforts on both the individual and collective levels such as the Charter of Rights for Persons with Autism. Society is beginning to evolve from mere awareness and acceptance of autism to *appreciation* for individuals on the autism spectrum as fully contributing members of the world community.

This societal movement is evidenced by the recent rise of organizations such as Specialisterne in Denmark that outsource people with autism, primarily in the information technology sector, for skills they have *precisely* because they are on the autism spectrum – while at the same time accommodating for differences resulting from being on the autism spectrum. Adhering to the following tenets will help preserve the rights of individuals on the autism spectrum to maintain their right to the pursuit of happiness and all that it engenders. Let's all build on the great work that has begun on...

- Accepting people on the autism spectrum for who they are as opposed to trying to make them something they aren't.
- Shifting the role of advocacy from guardians of rights of people on the autism spectrum to facilitators in adhering to those rights.
- Developing greater society awareness of the Charter of Rights for People with Autism and similar document should be a good first step.
- Striving to connect and establish common ground with individuals on the autism spectrum where they are developmentally, cognitively, emotionally, etc. before asking them to join us in our world.
- Developing self-awareness of strengths and challenges to the greatest extent possible for individuals on the autism spectrum.
- Education of individuals on the autism spectrum in effective self-advocacy skills.
- Shifting towards *appreciation* of individuals on the autism spectrum for who they are.

***The time to continue is now!***

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## **Stephen Shore Ed.D.**



Diagnosed with “Atypical Development and strong autistic tendencies” and “too sick” for outpatient treatment Dr. Shore was recommended for institutionalization. Nonverbal until four, and with much support from his parents, teachers, wife, and others, Stephen is now a professor at Adelphi University where his research focuses on matching best practice to the needs of people with autism.

In addition to working with children and talking about life on the autism spectrum, Stephen presents and consults internationally on adult issues pertinent to education, relationships, employment, advocacy, and disclosure as discussed in his books *Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome*, *Ask and Tell: Self-advocacy and Disclosure for People on the Autism Spectrum*, the critically acclaimed *Understanding Autism for Dummies*, and the newly released DVD *Living along the Autism Spectrum: What it means to have Autism or Asperger Syndrome*.

President emeritus of the Asperger’s Association of New England and former board member of the Autism Society, Dr. Shore serves in the Interagency Autism Coordinating Committee, Asperger Syndrome and High Functioning Autism Association, and other autism related organizations.