

Link



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Autism - Europe

Autism-Europe X International Congress

70 years of autism research – how far have we come?

New definition of autism in the DSM-5

Finland-Bangladesh solidarity project for autism



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Edito



Dear friends,

Happy New Year, we wish you much happiness and success in 2014!

In this edition, you will find the highlights of our 10th International Congress on the theme 'New Dimensions for Autism' which was held in Budapest in September 2013. We were glad to welcome so many of you who joined us there, not only for the congress itself, but also to celebrate the 30th anniversary of Autism-Europe. The Congress focused on the most recent developments across the field of autism including topics that have generated much interest recently, such as new opportunities in the area of information and communications technologies (ICT), best practices in service provision and ensuring quality of life for people with autism as they become elderly.



As reflected by our congress, knowledge about autism is constantly evolving, and so are the diagnostic criteria for autism. There has been a lot of debate lately around the new edition of the Diagnostic and Statistical Manual (DSM5) and we hope that this edition of *LINK* will help you to get a clearer picture of the implications of the new diagnostic criteria and what is at stake for the autism community.

Sharing knowledge about autism and solidarity are important values for our organisation. A great example within our network and beyond is the cooperative project in the field of autism between organisations in Finland and Bangladesh that is featured in this issue.

Finally, we are also delighted to introduce our three new member associations, and to inform you that Autism-Europe now has members from the Atlantic to the Urals!

We hope you enjoy reading this edition.

Yours sincerely,

Zsuzsanna Szilvasy
President

Aurélie Baranger
Director

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10th Autism-Europe International Congress 2013

Autism-Europe's 10th international congress was held in Budapest, Hungary on September 26 to 28, 2013.

Around 1,000 parents, professionals and people with autism from 56 countries around the world gathered to discuss topics following the congress theme of 'new dimensions for autism' in which people with autism and their families can fully enjoy their human rights and a better quality of life.

The congress opened with a ceremony featuring Princess Marie of Denmark, and covered the latest developments in the field of autism, including causes, genetics, diagnosis, early intervention, treatments, education, support, employment, rights and policies. It also included sessions on topics that have generated much interest recently, such as new developments in information and communications technologies (ICT), best practices in service provision and ensuring quality of life for people with autism as they grow older.

Keynote speakers included Prof. Sven Bölte, Prof. Tony Charman, Dr. Katarzyna Charwarska, Dr. Joaquin Fuentes, Prof. Francesca G. Happé, Prof. Rita Jordan, Prof. Nancy Minshew and Prof. Fred R. Volkmar, Prof. György Gergely, Dr. Miklós Győri, Dr. Krisztina Stefanik, Dr. Virág Bognár, Theo Peeters and Ros Blackburn.

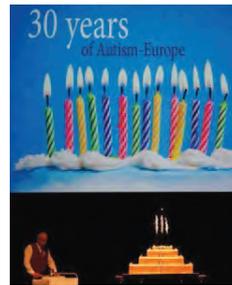
Hosted by the Hungarian Autistic Society, this congress was an historic occasion, marking both the 10th Autism-Europe International Congress and the 30th anniversary of the founding of Autism-Europe.

The congress also marked Autism-Europe's 'European Days of Autism' in which activities are conducted to raise awareness of autism around October each year.

As part of the congress, an online exhibition of art by people with autism was held by Autismo Burgos, in which prizes were awarded to the best artworks according to an online vote.

In addition, a gala dinner was held in a traditional Hungarian ranch style venue in Lajosmizse, 40 kilometres from Budapest, with horse shows, carriage rides and traditional dances.

Autism-Europe's congresses are dedicated to sharing advances in practical and scientific knowledge about autism to a broad audience. The congress is held every three years and the next one will be held in September 2016 in Edinburgh, Scotland, hosted by the National Autistic Society.



Kelemen Petra



Kelemen Petra



Kelemen Petra



Kelemen Petra



Kelemen Petra

Images: At the Autism-Europe X International Congress.

70 years of research on autism – how far have we come?

Professor Patricia Howlin

At the recent Autism-Europe International Congress in Budapest, Professor Patricia Howlin described the current state of autism research. She provided a concise summary of how far we have come in our understanding of autism as a result of the past 70 years of research, and what the research priorities should be in the near future.

It is now 70 years since psychiatrist, Leo Kanner, first described the condition that is known today as 'autism'. This would seem to be a good opportunity, therefore, to attempt to review the changes that have taken place in our understanding of autism over the past seven decades as well as to examine a number of current issues that are the topic of debate and controversy.

Prevalence of autism

For many years post-Kanner, autism was considered to be a rare condition (occurring in only around four per 10,000 children), mainly associated with moderate to profound intellectual disability, and which occurred only very infrequently in children with other disorders such as Down syndrome or cerebral palsy, etc. However, current estimates are consistent in indicating a much higher prevalence of around one per cent. It is also clear that autism is not, as initially believed, almost always associated with intellectual disability and, in fact, a significant minority (perhaps as high as 40 per cent) have an IQ in the average range (i.e. 70 or above). It is also evident that rates of autism are significantly higher among children with other genetic and developmental disorders, although the reason why these disorders are associated with a highly increased risk of autism remains an issue requiring much more research.

Causes of autism

A further source of research and controversy concerns the causes of autism. Beliefs about causation have changed back and forth over the years, starting with Kanner himself. He initially believed that the signs of autism appeared so early in life that they must be due to "inborn disturbances of affective contact" (Kanner, 1943). Nevertheless, he subsequently wrote extensively on the "parental coldness and obsessiveness" that he perceived in many parents (Kanner, 1949). Although challenged by those who recognised autism as a developmental disorder present from birth, this notion of "refrigerator" parents took many years to dispel, causing many families great distress. Early suggestions that autism might, nevertheless be due to genetic causes were also dismissed (e.g. Rutter, 1967) but twin and family studies conducted in the 1970s and 80s began to provide strong evidence of the highly heritable nature of autism. However, despite the claims that appear from time to time in the media suggesting that the "gene for autism" has been discovered, the genetic mechanisms involved remain uncertain. Both common and rare genetic variations have been identified in families with a child with autism, but the role of these variants is unknown. Moreover, many of these variants have also been identified in other psychiatric conditions such as schizophrenia, depression, bipolar disorder and ADHD (Smoller et al., 2013).

Somewhat paradoxically perhaps, the results of recent genetic research have led to increased awareness of the importance of environmental factors. As early as the 1970s, research had



shown that the rubella virus was associated with a substantially increased risk of autism. In the 1990s, studies of Romanian orphans had highlighted the finding that symptoms very similar to autism (so-called 'quasi autism') could result from severe physical and emotional deprivation. More recently, too, autism has been associated with increased maternal and paternal age. For example, it is suggested that de novo mutations may be due to environmental effects (e.g. paternal age Sanders et al., 2012) and that these new, spontaneous mutations may then be passed on, raising the risk of developing autism in the next generation. There is also a growing body of research into other possible environmental factors that may have an effect in the pre-natal or early post-natal periods. These include pollutants and toxins of various kinds, although so far no direct links have been found. The postulated association between autism and vaccines has also been widely discredited.

Classification of autism, Asperger syndrome and other disorders

Classification issues are a further issue of contention at the present time. Kanner believed that autism was "the earliest manifestation of childhood schizophrenia" noting that "I do not believe that early infantile autism will at any future time ...be separated from the schizophrenias" (1949). During the 1950s and 60s terms such as "early childhood schizophrenia" or "child psychosis" were often used to refer to children with autism. Indeed the journal we know today as *Journal of Autism and Developmental Disorders* was originally called the *Journal of Autism and Childhood Schizophrenia*. Autism as a distinct disorder was not included in the US Diagnostic and Statistical Manual (DSM) classification system until DSM-III was published in 1980.

At that time, too, as well as in the subsequent DSM-IV (1994), diagnostic criteria were based on impairments in 3 core areas (social; communication; repetitive behaviours). However, DSM-IV also incorporated autism within a group of other 'pervasive developmental disorders' that included Asperger's disorder, autistic disorder, Rett's disorder; childhood disintegrative disorder and Pervasive Developmental Disorder not otherwise specified (including atypical autism). Influenced by research suggesting that these diagnostic sub-categories (especially autistic disorder, Asperger syndrome and PDD-NOS) were being used inconsistently and unreliably, even when based on the same diagnostic instruments, together with the fact that impairments in communication and social interaction almost invariably go together, DSM-5 has introduced two major changes. Firstly, there are now just two core domains (1. Social-communication impairments; and 2. Repetitive and restricted patterns of behaviour/interests) and although criteria for reaching autism cut-off have been tightened, there is a very close correspondence between the symptoms included in DSM-IV and those contained in DSM-5.

However, DSM-5 has added modifications that may be more suitable for older, more able people with ASD and has also recognised the sensory sensitivities that are characteristic of many individuals. More controversially, however, DSM-5 has eliminated the subcategories of PDD and has just one category: Autism Spectrum Disorders. Not surprisingly, this decision has angered and worried those individuals with an existing diagnosis of Asperger syndrome, who fear not only that their group identity is being removed, but also that they may no longer be eligible for

support. Fear of losing services is also prominent among individuals with a diagnosis of PDD-NOS who are afraid they may no longer meet the new criteria for ASD.

Whether or not the new criteria will result in a loss of services for some, or an increase or decrease in the number of people meeting the criteria will require much more research over the forthcoming years. It is also currently uncertain whether the new edition of the World Health Organisation's International Classification of Disorders (ICD-11) will follow DSM's changes. Rumour has it that it may go for just two core domains, but will keep the sub-categories of autism, including Asperger syndrome – but only time will tell.

Instruments for diagnosing autism

It is likely that the changes in classification systems will necessitate some (although probably not major) modifications to existing diagnostic instruments. Although there has been considerable progress in identifying brain areas or brain functions that may be implicated, such findings have, so far, not led to the development of bio-markers that can reliably detect abnormal biological processes in autism. Claims that imaging techniques, blood tests, or even tape measures (to identify abnormal head growth) may identify individuals at risk have yet to be substantiated. As yet there remains no alternative to diagnostic assessments being based predominantly on clinical expertise, careful behavioural observation and detailed informant reports.

Effectiveness of interventions

The past seven decades have also witnessed many changes in approaches to intervention. The early emphasis on psychoanalysis (both for the children and their parents) was replaced in the 1960s and 70s by a focus on remediation of the social, communication and behavioural difficulties characteristic of autism. Ivar Lovaas was among the first to demonstrate the potential effectiveness of behavioural techniques and both he and Eric Schopler (who developed the TEACCH programme) were instrumental in highlighting the crucial role of parents in therapy.

Highly intensive early behavioural programmes (EIBI) have been claimed to result in major intellectual and behavioural gains for many children, but in fact, although when compared with 'treatment as usual' EIBI tends to result in greater improvement at a group level, individual change is much more variable, and not all children or their families respond well to programmes of this kind.

Moreover, there are many other programmes that have been shown, in randomised control trials, to be effective. For pre-school children these include the Early Start Denver Model; interventions to enhance joint attention, parent-child reciprocity and symbolic play, and training in behavioural management programmes for parents. For older children, successful trials have been conducted on the Picture Exchange Communication System (PECS) and a number of different approaches to improve deficits in social skills or emotional understanding (e.g. Theory of mind). Nevertheless, although the findings are encouraging there is still no evidence that any one high quality, specific intervention is superior to any other. There remains great variation in treatment response (both among individual children and according to the different domains assessed); evidence of generalisation to new skills or new settings is limited and there is no evidence of long-term impact

or significant improvements in functioning in later childhood/ adolescence. Claims, for example, that two years of EIBI result in significant lifetime savings are totally spurious. Research into the individual characteristics of children or families that are related to outcome is also in its infancy although more recent treatment trials are beginning to focus much more on factors that influence the outcome of treatment.

Diversity of research participants

It is important, too, to recognise that most intervention research continues to focus on children who come predominantly from relatively well functioning, middle class families who have the resources to participate in clinical studies. This excludes the majority of children with ASD and future research must begin to include these under-represented groups to improve understanding of intervention effectiveness for children with ASD (Kasari and Patterson, 2012). A further need is to focus more on the development of effective short term programmes that will help to improve access to high quality treatment for a majority of children with autism, not just the privileged few.

Research on adults with autism

Finally, it is crucial to recognise that autism is not a childhood disorder. Autism does not disappear at age 18, but unfortunately most interventions and support networks do! Several recent studies and systematic reviews have highlighted both the scarcity of studies of adults with autism and the poor quality of what little

Patricia Howlin

Patricia Howlin is Emeritus Professor of Clinical Child Psychology at King's College, London, and Professor of Developmental Disorders at Sydney University. She has worked with individuals with autism and their families for many years and has published widely on this topic. Her current research focuses on outcomes for older adults with autism and she is particularly concerned about the current lack of evidence based interventions and services for adults with ASD.

intervention research does exist. As highlighted by Piven and colleagues (2012) we need systematic studies on the characteristics (behavioural, neuropsychiatric and medical) associated with ageing in autism, and potential interventions – both individual and societal – that may improve outcome and quality of life. If recent advances in treatment programmes for very young children can be applied across the life span, then children with autism now growing up may face a more positive future.



Sachin Ghodke



Invitation

to Autism-Europe's 2014 Annual General Assembly

Luxembourg :

In accordance with the statutes of our organisation, we are pleased to invite you to attend the Autism-Europe Annual General Assembly, which will take place in Luxembourg on May 3, 2014.

Agenda :

- Presentation of the executive committee report
- Presentation of the Activity Report: 2013
- Presentation of the financial report: 2013
- Presentation of the Work Programme 2014

In conjunction with this meeting, a study visit to local autism support services will also take place on Friday May 2, and an Autism-Europe Council of Administration meeting will be held on Sunday May 4 (in the morning).



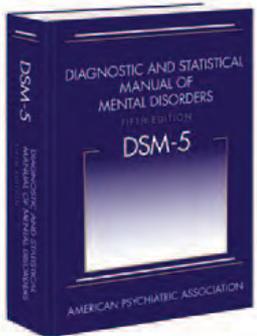
The meeting will be hosted by Fondation Autisme Luxembourg.

All the working documents related to these meetings will be emailed to the registered participants at a later date.

For more information, please contact
Autism-Europe secretariat:
secretariat@autismeurope.org

*Image (top) : Bourglinster Castle in Luxembourg.
Image (bottom) : The city of Luxembourg.*

New criteria for diagnosing autism under the DSM-5



As new research findings gradually lead us to a better understanding of autism, the criteria for a diagnosis of autism must continuously be revised. Last year, a new classification of autism in the latest edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) attracted much public attention. In this article, Dr Giacomo Vivanti and Dr Donata Pagetti Vivanti explain the meaning of these changes.

The DSM-5 is the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), edited by the American Psychiatric Association. The DSM is a classification of mental disorders that is used as a reference tool for diagnosis by many health professionals.

Moreover, it is used for research purposes and for elaborating public health statistics. The DSM is one of the world's two most commonly used manuals to classify mental disorders (the other one is the International Classification of Diseases (ICD-10), published by the World Health Organisation).

The changes introduced in the fifth edition of the DSM (DSM-5) reflect a significant departure from the diagnostic criteria that have been used in past decades to diagnose autism and related conditions. Initially classified under the label of 'childhood schizophrenia' in the first edition which was published in 1952, the diagnostic concept of autism has been subject to a new definition in each of the subsequent editions of the DSM.

Each of these updates has been met with controversy, and the latest changes in diagnostic criteria, introduced in the fifth edition in May 2013, are no exception.



Evelynne Nove

Main differences between the DSM-5 and the DSM-IV

1. Definition

The DSM-IV, introduced in 1994, defined autism and related disorders as 'pervasive developmental disorders' (PDDs). This definition has been replaced in the DSM-5 by the term 'autism spectrum disorders' (ASDs). These are included in the broader category of 'neurodevelopmental disorders'.

2. ASD subtypes

In the DSM IV classification, the category of pervasive developmental disorders included five different subtypes of autism: autistic disorder, Asperger's disorder, childhood disintegrative disorder, pervasive developmental disorder – not otherwise specified (PDD-NOS), and Rett syndrome.

The DSM-5 has replaced four of these subtypes (autistic disorder, Asperger's disorder, childhood disintegrative disorder and PDD-NOS) with one central diagnosis, 'autism spectrum disorder' (ASD). Rett syndrome is no longer included in the DSM. Rather than making a distinction between different subtypes, the DSM-5 diagnostic definition of ASD specifies three levels of symptom severity, and the intensity of the support needed.

3. Clinical features

The diagnostic definition of autism in the DSM-IV was characterised by three core symptoms (the triad):

- a. impaired social reciprocity;
- b. impaired language/communication;
- c. restricted and repetitive pattern of interests/activities.

In the DSM-5, there are now just two symptom categories :

- a. 'social communication deficits' (combining social and communication problems); and
- b. 'restricted/repetitive behaviours'.



The symptom categories 'social communication deficits' and 'restricted/repetitive behaviours' overlap partially with those in the DSM-IV, with two relevant changes:

- a. 'language impairment/delay' is no longer included in this symptom category in the DSM-5;
- b. a new clinical feature 'unusual sensitivity to sensory stimuli', that was not included in the DSM-IV; has been incorporated in the repetitive behaviours.

4. Onset

A further change is that the diagnostic criterion of onset of autism spectrum disorders before 36 months of age used in the DSM-IV is replaced with the following 'open' definition in DSM-5: "Symptoms must be present in early childhood, but may not become fully manifest until social demands exceed limited capacities".

5. Differential diagnosis

The DSM-5 introduces a new diagnostic label within the category of 'language impairments': 'social communication disorder'. The diagnostic features of this category partially overlap with that of ASD, as children diagnosed with social communication disorder are required to have an "impairment of pragmatics" as well as an impairment in the "social uses of verbal and nonverbal communication". However, the additional presence of fixated interests and repetitive behaviours excludes the possibility of a diagnosis of social communication disorder. Therefore, the occurrence of repetitive behaviours is essential for the differential diagnosis of ASD.

Rationale for Changes

The changes introduced by the DSM-5 are driven by research data. The removal of the diagnostic subtypes of PDD seen in DSM-IV is based on studies showing that :

- a. the distinction among the DSM-IV subtypes is inconsistent over time;
- b. the application of the diagnostic subtypes can be inconsistent across sites (e.g. the same child could be diagnosed as having Asperger's disorder at one site and autistic disorder at another);
- c. the differences in social and cognitive abilities between subgroups are better defined in terms of a continuum, rather than separate subtypes;
- d. there is little evidence for any significant difference in the genetic risk of a person having either autistic disorder or Asperger's disorder (i.e. studies based on siblings of children with autism spectrum disorders show that the prevalence of autistic disorder and Asperger's disorder among the siblings is approximately the same). The findings of biological studies (e.g. biomarkers, functional brain imaging and eye-tracking studies) also show little evidence of any significant difference in genetic risk of a person having one condition or the other.

Revised diagnostic criteria for autism spectrum disorder in the DSM-5

- A - Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:
 - 1 - Deficits in social-emotional reciprocity;
 - 2 - Deficits in nonverbal communicative behaviours used for social interaction;
 - 3 - Deficits in developing, maintaining and understanding relationships.
- B - Restricted, repetitive patterns of behaviour, interests or activities as manifested by at least two of the following, currently or by history:
 - 1 - Stereotyped or repetitive motor movements, use of objects, or speech;
 - 2 - Insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal or nonverbal behaviour;
 - 3 - Highly restricted, fixated interests that are abnormal in intensity or focus;
 - 4 - Hyper- or hypo- reactivity to sensory input or unusual interest in sensory aspects of the environment.
- C - Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- D - Symptoms cause clinically significant impairment in social, occupational or other important areas of current functioning.
- E - These disturbances are not better explained by intellectual disability (intellectual developmental disorder), or global developmental delay.

The relevance assigned to the presence of repetitive behaviours and the elimination of the language-related criteria is based on recent studies documenting that:

- a. repetitive behaviours, including abnormal sensory responses, emerge early in the development of children with ASD;
- b. unlike language difficulties, they are a distinctive feature of ASD.

Finally, the new diagnostic category of social communication disorder in the DSM-5 has been introduced because some children might present impairments in the social use of communication without having repetitive/restricted behaviours, as documented by Rapin & Allen¹, 1983.

Criticisms of the DSM-5

A number of concerns have been raised by scholars and advocacy groups about the clinical, research and cultural implications of these changes. The most common criticism of the DSM-5 definition of ASD is that the new criteria are too narrow and could result in excluding some individuals from a diagnosis of autism and therefore excluding them from access to services they need.

A number of studies appear to support this concern. Some studies² found that a significant proportion (10-40 per cent) of individuals meeting the DSM IV criteria for a diagnosis of ASD would not meet the new criteria under the DSM-5.

Another common criticism concerns the introduction of the new diagnosis of social communication disorder. It is unclear how this diagnosis is related to the ASD diagnosis and, as it is a new diagnosis, there are doubts about its practical use in terms of treatment strategies to be recommended and whether individuals diagnosed with this condition will be able to gain access to services relevant to their condition.

Some self-advocate organisations also argue that incorporating Asperger disorder into the category of autism spectrum disorders without any distinction from autism will undermine the identity of affected people. Nevertheless, the approach of DSM-5 to the

sub-classification of ASD, by taking into account the level of support needed, is more consequent to the rights-based approach enshrined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). According to the UNCRPD approach, disability is – and must be considered as – diverse. The inherent dignity and value of every human being should be fully recognised, regardless of the type or severity of his or her disability. As a consequence, a diagnosis or sub-diagnosis should never be the grounds on which to build the identity of a person or group of people. At the same time, according to the UNCRPD definition of disability, no person should be considered disabled against his or her will.

Finally, classifying Asperger disorder as a specific subtype of ASD entails an even higher risk for affected people to be excluded from support they may need and services, mainly because the myth that people with Asperger disorder are geniuses is still very prevalent.

Conclusion

The changes introduced by the DSM-5 are based on scientific evidence, rather than on the grounds of politics or lobbying. Nevertheless, there are some concerns about adopting the new classification system, including the possibility that some individuals might no longer meet the diagnostic criteria for ASD.

It is imperative therefore that the scientific community studies the impact of the changes to the DSM in the real world and that policy makers ensure that the introduction of the new criteria will not result in changes in coverage policies for support services that will exclude people with ASD from accessing them.

More information on the DSM-5 is available at: www.dsm5.org

1. Rapin, I., & Allen, D. (1983). Developmental language disorders: nosologic considerations. In U. Kirk (Ed.), *Neuropsychology of language, reading, and spelling*, pp. 155-184. New York: Academic Press.

2. Vivanti, G., Hudry, K., Trembath, D., Barbaro, J., Richdale, A., Dissanayake, C. (2013). Towards the DSM 5 Criteria for Autism: Clinical, Cultural and Research Implications. *Australian Psychologist*, 48, pp.258-264; Volkmar FR, Reichow B (2013). Autism in DSM-5: Progress and challenges. *Molecular Autism*, 4: 13.

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Vice President, European Disability Forum



Sachin Ghodke



European Disability Forum



Amaze

**AUTISM AND WORK.
TOGETHER WE CAN.**

World Autism Awareness Day | April 2



World Autism Awareness Day is coming soon! April 2, 2014

'Autism and work. Together we can.' campaign

In 2014, Autism-Europe members are conducting a common campaign to raise awareness across Europe about the needs of people with autism in the fields of education and employment. Currently, between 76 and 90 percent of adults with autism are unemployed*. Adults with autism need access to post-school education, training and employment initiatives to enable them to join the workforce. Education and employment can also enable them to overcome the social exclusion they often face, taking more active roles in their communities and becoming more independent.

Throughout the year, Autism-Europe will raise awareness of positive initiatives for the employment of people with autism. Indeed, a growing number of companies are discovering that the specific skills of people with autism can be a great asset for their business. This trend should therefore be celebrated and fostered!

Activities and events in Europe

Once again, Autism-Europe members are organising a wide range of events across Europe to mark World Autism Awareness Day. What are you doing to raise awareness of autism on April 2? Whatever you are planning, Autism-Europe would love to know about it so we can help to promote it via our website, Facebook, Twitter, etc!



If you need inspiration and ideas for events, you could check out our website, where you can find details of all kinds of creative events that were held by our members to mark World Autism Awareness Day in 2013 – from concerts, film screenings and art exhibitions to balloon releases, flash mobs, and even a walking a tour of 610 km!

Around the world, many cities are also joining the 'Light It Up Blue' initiative by US organisation, Autism Speaks, with landmark buildings lit up in blue for the evening on World Autism Awareness Day.

Please send details of what you are doing, where and when to: assistant@autismeurope.org

Details of our members' events and activities for World Autism Awareness Day 2013:

<http://www.autismeurope.org/activities/world-autism-awareness-day/world-autism-awareness-day-2013-2.html>

About World Autism Awareness Day

On December 18, 2007, the United Nations General Assembly adopted resolution 62/139, tabled by the State of Qatar, which declares April 2 as World Autism Awareness Day each year.

This UN resolution is one of only three official disease-specific United Nations Days and aims to bring the world's attention to autism, a pervasive disorder that affects tens of millions.

The World Autism Awareness Day resolution encourages all Member States to take measures to raise awareness about autism throughout society and to encourage early diagnosis and early intervention. It also expresses deep concern at the high prevalence rate of autism among children in all regions of the world and the consequent developmental challenges.

* Sources: *The National Autistic Society via the Association of Graduate Careers Advisory Services, Autism Speaks; Specialisterne; Aspiritech; United Kingdom Office for National Statistics (2001), Census Report.*

Images:
(top) The children and teachers of the Sitborice Primary School in Breclav, Czech Republic.
(bottom) The Bourse in Brussels lit up in blue for World Autism Awareness Day.



A new tool to simplify text for people with autism

People with autism often experience exclusion from society as they struggle to gain access to education, training, employment and social activities. This exclusion stems not only from social attitudes, but also from the difficulties that people with autism often face in understanding information and social communication. For this reason, a new software program, called Open Book, aims to provide assistance in understanding written information by simplifying text for people with autism. Autism-Europe is a partner in the research project that is developing this tool, and here we bring you information about how it will work.

Open Book will simplify text, converting it into a form that people with autism can understand more easily. It is a bit like Google Translate, but instead of translating from one language to another, the tool will adapt the text from one language into a more accessible version of the same language.

It will take an original text and adapt it to provide the user with a new simplified document, which contains simplified language, as well as a summary, pictures and document navigation tools.

The tool is being developed by a team of computer programmers from universities who specialise in language technology and professionals in the field of autism from across Europe.

Reading difficulties for people with autism

As a result of their condition, people with autism can experience difficulties in:

- Comprehending speech and writing;
- Interpreting figurative / non-literal language (such as metaphors and expressions);
- Understanding complex instructions;
- Deriving the meaning or gist of written documents.

These difficulties in understanding everyday communications such as letters, bills and medical documents can lead to significant barriers to participation and inclusion in all aspects of society, including education, employment, health care and social activities.

Open Book aims to reduce these barriers by empowering people with autism to read a broad range of texts with confidence and autonomy.



How Open Book works

Open Book utilises language technology to reduce complexity, remove ambiguity and improve the readability of written documents.

This process includes:

1. Replacement of...
 - long complex sentences with several short, simple sentences;
 - informal expressions with regular language.
2. Provision of definitions for words and expressions that are...
 - long/technical;
 - ambiguous;
 - non-literal (eg. metaphors);
 - related to emotions.
3. Addition of...
 - images ;
 - concise summaries;
 - document navigation tools for long documents.

The tool is designed for people with autism who do not have an intellectual disability, but do experience difficulties with understanding written texts. As autism encompasses a spectrum of symptoms that vary in severity among individuals, the software can also be personalised, enabling users to adapt documents to match their own reading and comprehension abilities.

Developed by working with people who have autism

Open Book is not just being developed *for* people who have autism, it is being developed *with* people who have autism. The team developing the tool is working with a large group of people who have autism across three countries to ensure that the tool will meet their diverse requirements.

The research conducted to date by the Open Book team has included questionnaires and interviews conducted with adults and teenagers who have autism as well as questionnaires for their parents and carers. These were conducted in the United Kingdom, Spain and Bulgaria in each of these languages. The results of these questionnaires have identified and confirmed many reading comprehension difficulties faced by people with autism. They have also determined numerous features that can be included in the Open Book software to assist users to overcome these difficulties.

During the last year of the tool's three-year development process, further research will be conducted under clinical conditions with people who have autism to evaluate the effectiveness of the software in improving their reading comprehension.

The results of this research will be utilised in the final year of the tool's development to ensure its effectiveness.

To date, very few software programmes for people with autism have been developed through such a rigorous process of researching user's needs and evaluating the software's effectiveness, making Open Book one of the most evidence-based tools currently available to assist people with autism.

Increasing social inclusion

By assisting people with autism to access written information, Open Book aims to increase their access to educational, vocational, cultural and social opportunities in Europe, and thereby increase their social inclusion and quality of life.

The project's coordinator, Professor Ruslan Mitkov, of the University of Wolverhampton, explains: "The project aims to assist people with autism to read documents with greater confidence and autonomy. We aim to help them break down some of the barriers they face in everyday life so they can increase their social inclusion and gain better access to educational, vocational, cultural and social opportunities in Europe."



"To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas."

- United Nations Convention on the Rights of Persons with Disabilities, Article 9.1

Developed by the FIRST Project



The Open Book tool is being produced by the FIRST (Flexible Interactive Reading Support Tool) Project. The FIRST Project is a collaborative research project bringing together experts in language technology, software development and autism.

The project partners include:

- University of Wolverhampton, UK
- Central and North West London NHS Foundation Trust, UK
- Universidad de Alicante, Spain
- Autism-Europe aisbl, Belgium
- Universidad de Jaen, Spain
- Parallel World Sdruzhenie, Bulgaria
- Deletrea SL, Spain
- iWeb Technologies LTD, UK
- Kodar OOD, Bulgaria

More information

Open Book has been in development for two years so far, and the final version is expected at the end of 2014. For more information about the FIRST project, events and training, and to sign up for updates via our online newsletter: www.first-asd.eu or email us: contact@first-asd.eu

The project leading to this software product is partially funded by the European Commission under the Seventh Framework Programme (FP7-2007-2013) for Research and Technological Development under grant agreement n° 287607. This publication reflects the views only of the authors, and the Commission cannot be held responsible for any use which may be made of the information contained therein.

Including

people with autism at work in the arts and culture sector

Miren Hurtado

Employment and training opportunities are essential to ensure the full inclusion of all citizens in economic, social and cultural life in Europe. In Finland and the United Kingdom, two autism organisations have developed initiatives to promote employment and training opportunities for people with disabilities, including people with autism, in the arts and culture sector.

'Puoltaja' – a magazine made by self-advocates

'Puoltaja' (meaning 'advocate' in Finnish) is a webzine (online magazine) entirely written and produced by a group of volunteers on the autism spectrum (most of whom have Asperger's syndrome) and people with other disabilities.

Janne Fredriksson from the Finnish Association for Autism and Asperger's Syndrome explains that "In Finland, the mainstream media is becoming more interested in portraying people with autism as self-advocates". When he observed that many people on the autism spectrum in Finland were actively writing in online forums and on social media websites, he came up with the idea to create *Puoltaja* as a platform where they could develop their own stories for a broader audience.

The main purpose of *Puoltaja* is to advocate for 'autism culture'; it takes a rights-oriented approach and gives a voice to the opinions, interests and positions of people with autism. It also aims to raise

awareness about autism among the general public and challenge some predominant stereotypes around people with autism.

Puoltaja is published four times a year and currently has around 2,000 readers, including people with autism, their families and professionals. The volunteer staff hold editorial meetings twice a month to discuss the content of the magazine and the distribution of the tasks. Sometimes, they report on events and interview professionals, including special education teachers, psychologists and life coaches, and they encourage people with autism to send them their artworks for publication in the magazine.

For the volunteer staff who works as editors, *Puoltaja* provides the opportunity to develop practical skills for employment such as writing, editing and web design.

In 2014, the group is hoping to expand their activities to create a *Puoltaja* radio programme, and are already in contact with a local radio station in Helsinki.



Image: Puoltaja magazine online.

'The Gallery on the Corner' – a social and commercial business

'The Gallery on the Corner' is a commercial art gallery and studio located in Edinburgh which offers employment and training opportunities in commercial art and retail for adults with autism.

The gallery and studio were opened in 2010 by 'Autism Ventures Scotland', an organisation established by Autism Initiatives to create employment opportunities for people with autism. The gallery aims to provide a platform to exhibit and sell artwork produced by artists who have autism or other physical or mental health conditions and those from disadvantaged backgrounds, in a high-profile location in a major capital city.



Image: Puoltaja magazine staff.



Images: (above and on page 15) Artworks by the trainees at The Gallery on the Corner.

Susie Anderson, Manager of The Gallery on the Corner explains that "The gallery is based on a social enterprise model which combines the sustainability of the project with providing real work experience in real work environments for adults with autism as part of a route to employment".

The gallery runs one-year traineeships for adults with autism in art and retail. The trainees work as part of a studio team, developing skills in producing commercial art for exhibition and sale at the gallery and in other venues. The gallery also helps them to develop transferable skills that could be used in other areas of employment, including customer service and computer skills.

The gallery exhibits artworks by their trainee artists that rotate monthly, and as works are sold. The monthly exhibitions are sometimes held in conjunction with other organisations such as charities, art projects and schools for students with special needs. Each exhibition has an opening event which allows the work of the artists to be celebrated.

As part of its social enterprise approach, the gallery also offers artwork services in which paintings and prints by the gallery's trainees can be exhibited or hired for long periods of time by

"The gallery is based on a social enterprise model which combines the sustainability of the project with providing real work experience in real work environments for adults with autism as part of a route to employment".

companies to decorate their business premises. The gallery and studio can also be hired as a venue for events.

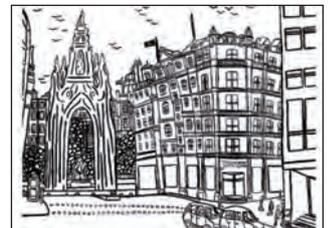
The gallery has enjoyed much success already. The first group of trainees was awarded for their work at the gallery at the National Scottish Consortium for Learning Disability Awards in 2011. In addition, some trainees have become self-employed artists, and found jobs as support workers and trainee proof readers.

More information : www.thegalleryonthecorner.org.uk

Count Me In Project

The *Puoltaja* magazine and The Gallery on the Corner will soon be featured alongside other good practices in a publication by a European Union-funded project titled 'Count Me In', which runs from 2012 to 2014. As part of this project, they are promoted as examples in providing employment and training opportunities for people with disabilities in the arts and culture sector. Autism-Europe is one of a number of partner organisations involved in this project.

More information : www.count-me-in.eu



"States Parties recognise the right of persons with disabilities to work, on an equal basis with others.(...) States Parties shall (...) promote employment opportunities and career advancement for persons with disabilities in the labour market, as well as assistance in finding, obtaining, maintaining and returning to employment."

- United Nations Convention on the Rights of Persons with Disabilities, Article 27.1.e

"States Parties shall take appropriate measures to enable persons with disabilities to have the opportunity to develop and utilise their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society."

- United Nations Convention on the Rights of Persons with Disabilities, Article 30.2

Finnish

solidarity project is improving the quality of life of people with autism in Bangladesh

In Bangladesh, children and young adults with autism now have better education and training opportunities as a result of a co-operative development project between autism organisations in Finland and Bangladesh.

The Prerona Project (meaning 'the inspiration project') is a development initiative between the Finnish Association for Autism and Asperger's Syndrome (FAAAS) and the Society for the Welfare of Autistic Children (SWAC) in Bangladesh. The project takes a human rights oriented approach to developing an inclusive model of education for students with autism, addressing the training needs of young adults with autism and raising awareness. The project runs from 2007 to 2014, and it was made possible when the FAAAS secured funding from the Ministry of Foreign Affairs in Finland, as well as fundraising activities.

Autism in Bangladesh

In Bangladesh, children with autism who are fortunate enough to access medical services at all are frequently misdiagnosed and given antipsychotic drugs due to the lack of knowledge about autism among doctors and professionals. People with autism and their families often suffer from the stigma associated with autism. Parents are often frustrated and in a state of anguish over the lack of information and services that could enable them to help their children.

The mainstream education system in Bangladesh rarely meets the needs of children with autism and other disabilities, despite the fact that the country has ratified the United Nations Convention on the Rights of Persons with Disabilities and that the right to education is enshrined in its constitution. And the situation is much worse for children in rural and slum areas.

Currently, around 500 disability organisations are working to provide services for people with disabilities in Bangladesh, mainly concentrated in the capital city, Dhaka. There are now numerous schools for children with disabilities throughout the country, including around 20 schools in Dhaka.



Marja Helmi Noutinen

Developing an inclusive approach to education

The SWAC operates one of only three schools which work exclusively with children with autism in Bangladesh. The school is located in Dhaka and provides educational services for 116 students.

The first phase of the Prerona Project (from 2007 to 2011) increased the number of children with autism who are gaining a basic education and developed the educational facilities at the SWAC's school in Dhaka. The co-operative development project has provided basic teaching materials and technology such as computers to the school.

The school now also offers a student exchange programme in collaboration with mainstream schools with the aim to increase the inclusion of students with autism in the wider community and raise awareness about autism.

In addition, the Autism Visible Programme (developed by the Prerona Project) works to increase the inclusion of the students with autism in their communities by arranging weekly excursions to local shops, banks, factories, museums and parks.



Marja Helinä Nuortinen

The project also provides free education and food to children from low income families in slum areas of Dhaka. As part of this initiative, two teachers provide free education to groups of 8 to 12 students, five days per week .

Training opportunities

The second phase of the project (from 2012 to 2014) is focused on the situation of young people with autism at the SWAC's school. The school has set up a work and activity centre to help students with autism with the transition to adult life. Students receive vocational education and training in hospitality, housekeeping and manual crafts. They also learn practical skills for everyday life such as cooking, cleaning and sewing, and develop their behavioural and social skills. Every year, exhibitions are held to showcase the students' artworks and handicrafts.



Marja Helinä Nuortinen

Raising awareness about autism

The Prerona Project also runs campaigns with partner organisations to raise awareness of the rights of people with autism among policy-makers and to create positive changes in social attitudes towards people with autism in Bangladesh.

Following Bangladesh's first World Autism Awareness Day campaign in 2008 and Bangladesh's first autism conference in 2009 (both organised by the SWAC and their partner organisations) commitments were made by government representatives in support of the rights of people with autism under the national policy for education and children. The Bangladesh Bureau of Statistics has also included autism in its population census since 2011, but the national government has yet to make any official recognition of autism as a disability.



Marja Helinä Nuortinen



Marja Helinä Nuortinen

Images: Activities and meetings as part of the Prerona Project.

Polish Parliament passes the Charter for Persons with Autism



The Polish Parliament has passed the 'Charter for Persons with Autism', which was originally written by Autism-Europe.

The Charter for Persons with Autism was translated and modified to adapt it to the Polish context, in which the majority of people with autism do not benefit from existing support programmes for people with disabilities.

The text of the Charter was unanimously passed by the Polish Parliament as a resolution in July 2013, and is expected to draw Polish policy makers' attention to the needs of people with autism.

The passing of the resolution is the result of years of advocacy work by autism organisations, including SYNAPSIS Foundation, and government representatives in Poland.

A key factor in convincing the Polish Parliament to adopt the Charter at national level was the fact that the Charter had been adopted as a written declaration by the European Parliament in 1996 (following extensive advocacy work by Autism-Europe).

It is hoped that the resolution will lead policy makers to take into account the specific needs of people with autism within legislation related to the situation of people with disabilities in Poland.

For more information, contact Agnieszka Rymsza, SYNAPSIS Foundation: a.rymsza@synapsis.waw.pl

Choir singers unite to raise money for Autism-Europe in Paris



A group of choir singers raised money for Autism-Europe at an event called 'Venite Cantemus' on December 7, 2013.

At this unique event, choir singers came to Paris from across Europe to sing a

beautiful rendition of Handel's 'Messiah' together at the Madeleine Church.

Autism-Europe is very grateful for the generous support that was shown by the Venite Cantemus organisers and participants in helping to improve the quality of life of people with autism.

More information: www.venitecantemus.com

L'Oréal initiative to employ people with autism in Italy



Cosmetic company, L'Oréal, has recently embarked on an initiative to employ people with autism in Italy.

As part of the company's measures to ensure diversity in the workplace, the company's 'Integration of Adults with Autism' project works with an Italian autism association named Fondazione TEDA to employ adults with autism within its operations.

Representatives of L'Oréal Italy participated in the Autism-Europe's last Council of Administration meeting, which was held in Brussels on November 30 to December 1, 2013, as a first step in exploring possible collaborations in the employment of people with autism around Europe.

More information: secretariat@autismeurope.org

Autism-Europe spoke on equal access to healthcare at the European Parliament



Autism-Europe's Director, Aurélie Baranger, raised the concerns of people with autism in a talk at an event on equal access to healthcare at the European Parliament in October 2013.

The event, called 'It's our Year, give us a voice!', focused on active citizenship of people with disabilities through equal access to healthcare within the context of the European Year of Citizens 2013.

Ms Baranger's talk highlighted the specific healthcare needs of people with autism and the need to improve communication between healthcare professionals and patients with autism.

The event included a collaborative workshop between Autism-Europe and several other European disability organisations, which concluded with a list of recommendations for EU decision-makers and other relevant organisations to improve access to healthcare for people with disabilities.

The recommendations highlight the need for the review of relevant legislation, provision of accessible information and improved communication between medical professionals and people with disabilities.

More information: www.autismeurope.org/publications/autism-europe-position-papers-and-recommendations/

Autism-Europe's network of members expands to Russia

One of the first organisations to work with children with autism in Russia, 'Our Sunny World', has recently become a member of Autism-Europe.

Our Sunny World is a non-commercial, non-governmental organisation, founded in 1991 on the initiative of parents and professionals in the field of autism.

The circumstances for people with autism in Russia are quite difficult. Until recently, children with autism were usually placed in institutions, and in many regions of Russia this practice has still not changed. There is currently no state support for children with autism to receive effective therapies and there are no statewide diagnostic or therapeutic instruments and methods.

Our Sunny World, however, is currently providing support to more than 300 children from Moscow in its rehabilitation centre and also provides consultations to many additional families all over Russia.

Our Sunny World operates on a belief in the absolute value of everyone, without any dependence on their individual features. The organisation aims to provide rehabilitation for people with autism and other disabilities in a supportive environment to help them realise their full potential.

Over the past 20 years, guided by the experience of its specialists and by scientific research, the organisation has established a wide range of therapies, services and projects for children and adults with autism. Some of these include speech and language therapy and alternative communication methods (PECS). Since 2005,

Our Sunny World has been promoting the use of the Applied Behavior Analysis (ABA) method in Russia. In addition, the organisation provides arts, sports and social activities for people with autism and offers workshops and training to parents and professionals who come from all over Russia to attend.



Image : Training for professionals.

As children with disabilities in Russia are still often isolated from other children, in 1992 Our Sunny World held a rehabilitation camp that was attended by both for children with autism and other children.

The organisation also conducts research and publishes information on rehabilitation for children with autism, and works in collaboration with research institutes and other organisations that share the same aims, both in Russia and internationally.

Our Sunny World also conducts activities to raise public awareness of autism. These have included a meeting in the central square of Moscow and fostering the participation of Russian buildings in the 'Light it up blue' initiative to mark World Autism Awareness Day in 2012. The organisation has also been featured in major media outlets in Russia.

Representatives of Our Sunny World also participate in relevant government committees to advocate for better legislation and implementation of the rights of people with autism in Russia.

More information : www.solnechnymir.ru

Our Sunny World is now an associate member of Autism-Europe.



Image : Our Sunny World staff working with children with autism.



Images (above and right): Summer camp for children with autism and other children.



Supporting the social inclusion of children and adults with autism in the East Midlands region

NORSACA was founded in 1968 in Nottingham, in the United Kingdom, by a group of parents who were concerned about the lack of suitable education for children with autism in the East Midlands region. Since then, the organisation has been providing services for the inclusion of both children and adults with autism in their local communities for 45 years.

Skills development for adults

NORSACA's 'Work and Learn Centre' opened in 2011 in the town of Worksop. The centre provides opportunities for adults with autism to develop skills for employment, as well as personal development and social activities. The centre takes an individual approach to ensure that each adult with autism has a programme of activities that meets their own personal needs. It also includes a bicycle workshop in which participants can develop basic skills in bicycle repairs and maintenance, as well as an understanding of team work, road safety and responsibility.

Independent living services for adults

Supported living services are provided to help adults with autism to live, as independently as possible, in their own homes. The services are tailored to each individual's support needs, ranging from assistance for a few hours per week to assistance 24 hours per day. NORSACA's outreach services also provide one-to-one (or two-to-one if required) specialist support workers, either in the home or in the community.

Sutherland House School

Sutherland House School is a specialist school for up to 94 students with autism between the ages of three and 19 years. Since its beginning in 1970, the school has expanded to 5 sites in and around Nottingham. The school prepares individual education plans for its students and is committed to the principle of social

inclusion. Where appropriate, some of the school's students also spend periods in mainstream schools as part of their individual education plans. It employs a range of specialists including speech and language therapists, psychologists, music specialists and occupational therapists. The school has been rated as 'outstanding' by the Office for Standards in Education, Children's Services and Skills in England.

Support group for siblings

NORSACA also runs a support group for children aged between 8 and 12 years who have a brother or sister with autism. The children have the opportunity to explore their feelings, share their experiences and learn about autism in a confidential environment.

More information: www.norsaca.org.uk

NORSACA's support and information services include:

- a specialist school;
- play and leisure activities for children and young people;
- residential homes for adults;
- support services for independent living;
- outreach services;
- counselling for people with autism and their families;
- a support group for siblings;
- telephone advice;
- skills development and leisure services for adults;
- a diagnosis and assessment centre for children;
- training for parents, carers and professionals.



NORSACA is now an affiliated member of Autism-Europe.



Recreation, culture and advocacy for people with autism in Sardinia

Diversamente Onlus is an association of parents of people with autism and professionals based in Cagliari, on the Italian island of Sardinia. Founded in 2007, the organisation aims to promote better quality of life for people with autism and their families through the implementation of the 'Charter for Persons with Autism' (which was drafted by Autism-Europe and adopted as a Written Declaration by the European Parliament in 1996). Their work includes advocacy, awareness-raising and activities for people with autism in the fields of education, culture and sports.

Advocacy for the right to education

Diversamente Onlus works with several local school boards to promote best practices in the inclusion of students with disabilities, including students with autism. They also organise workshops and conferences at local public schools to raise awareness about autism, and to help teachers and students understand how to approach, and communicate with, people who have autism.

Information and awareness-raising

Every year, Diversamente Onlus holds an international short film festival, called 'AutisMovie', to raise awareness about autism. They have also created the 'Autismoteca'; a collection of books, journals, magazines and audiovisual materials which are available at the organisation's premises.

In addition, they recently translated and published a children's book titled 'il Silenzio di Camillo' ('The Silence of Camillo'); the story of a boy with autism who doesn't speak, in collaboration with Spanish organisation, Autismo Burgos, and produced a short film based on the book.

Recreational activities

The organisation conducts recreational activities for children with autism, including art and music workshops, hiking, swimming, and football and excursions to cultural festivals. During summer, they also organise a camp and trips to the beach or the swimming pool.

Working in collaboration with other organisations

To achieve their goals, Diversamente Onlus collaborates with local and regional governments, health authorities, and non-government organisations which share similar goals and concerns. In particular, the organisation collaborates with the Child Neuropsychiatry Centre at the Brotzu Hospital in Cagliari on research and projects for people with autism.

More information : www.diversamenteonlus.org

Diversamente Onlus' main goals include:

- Establishing multi-disciplinary centres for recreational and occupational therapy activities;
- Establishing training services for professionals and carers in the field of autism;
- Collaborating with other relevant organisations on projects for social inclusion, education, employment and sports;
- Collaborating with organisations that conduct research on autism spectrum disorders;
- Providing information and support to people with autism and their families;
- Conducting awareness-raising activities.

Diversamente Onlus is now an affiliated member of Autism-Europe.



Image : An autism awareness raising activity with students in Italy.



Image: President and Vice President of Diversamente Onlus.

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XI Autism-Europe International Congress



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