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Edito



Dear Friends,

On behalf of the executive committee of Autism-Europe, we would like to wish you all the best to you and your families for 2011.

Although 2010 has been a successful year for Autism Europe, we have all been deeply saddened by the deceases of Jacques Masson, one of the founders of the organization in 1983, and of Gilbert Huyberechts, president from 1989 to 2000, who died on December 13th in Luxembourg.

Gilbert greatly contributed to raise awareness of Autism at the European level. He will be remembered as a dear friend and was and will remain a true inspiration for those who defend the rights of people with complex dependency needs, and in particular with ASD.

This Link issue is dedicated to Gilbert.

The duty of Autism-Europe is to pursue their commitment. In this respect, Autism Europe's Congress "A Future for Autism", held in Catania in October, provided 1200 participants with a comprehensive picture of the substantial gains in knowledge during the last three years and their implications for intervention. A wide range of topics was discussed: from genetic features and neuro-biological findings to social and cognitive development, from diagnosis and classification to intervention and policies.

Since it is essential to disseminate and give everyone access to up-to-date and evidence-based information on autism, we are delighted to announce that videos of presentations of the Congress are now available for free on internet.

The end of the year was also marked by the official ratification of the UN Convention on the Rights of Persons with Disabilities on 23 December by the European Union. There is a lot of work ahead for its full implementation, but the institutions of the European Union will now have to endorse the values of the Convention in all policies under their competence ensuring mainstreaming of disability: from transport to employment and from information and communication technologies to development cooperation. It also means that they have to adjust the accessibility of their own buildings, their own employment and communications policy.

In 2011, Autism-Europe will work towards the implementation of the UN Convention, in cooperation with other organizations of the disability movement, in particular the European Disability Forum.

We will continue representing persons with ASD and raise awareness about their specific needs in partnership with the European institutions that have just adopted a Disability Strategy for the period 2010-2020. We would like to thank the European Commission for its support to help Autism-Europe combat discrimination experienced by persons with ASD throughout Europe. Autism-Europe has been selected as a key EU Disability network to benefit from the PROGRESS programme for equality and anti-discrimination 2011-2013.

We would also like to thank all of you once again for your precious support and expertise that are key to Autism-Europe. Please continue sharing your experiences and good practices with us through these pages. You will also find in this issue the invitation to the Annual General Assembly to be held in Athens in April 2011. Once again a happy new year to all of you!

Finally, 2011 is the European Year for Volunteering, and we would like to seize this opportunity to thank wholeheartedly all the volunteers across Europe who give their time and energy to support the cause and advocate for autism.

Evelyn Friedel
President of Autism-Europe

Aurélie Baranger
Director

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Activities



IX International Congress AUTISM-EUROPE A FUTURE FOR AUTISM

Catania, Italy
8 - 10 October 2010

The IX International Congress of Autism-Europe "A Future for Autism", held in Catania, Italy, 8-10 October 2010 provided a unique opportunity for updating and sharing knowledge on a wide range of issues concerning Autism, from genetic features and neurobiological findings to social and cognitive development, from diagnosis and classification to intervention and policies.

Some 1200 delegates, researchers, professionals, parents and self-advocates coming from everywhere in the world, enjoyed this unique opportunity to discuss with the best known scientists in the field of ASD their concerns and hopes for significant advances in terms of knowledge, provisions and proper support to persons with ASD in the world .

18 keynote speakers, 70 selected speakers and 185 selected poster exhibitors and other relevant personalities in the field of EU policies contributed to its success through the high quality and variety of their presentations, providing a

comprehensive picture of the substantial gains in knowledge during the last 3 years and their implications for intervention.

Progress in scientific knowledge has come particularly from a greater use of experimental designs, the application of eye-tracking methodology, the use of functional brain imaging, the 'baby-sibling' prospective studies.

Greater gains in the fields of prevention and intervention can be expected in the years ahead. A better Future for Autism, persons affected and their families is close.

The following report, while not exhaustive, summarises the more relevant issues which have been presented at the Congress.

GENETICS FINDING AND BRAIN DEVELOPMENT

The "autism genome project" (AGP) on > 1000 patients with ASD, confirmed rare pathogenic gene mutations affecting molecules (neuroligins, neurexin and SHANK 3), which are involved in the synaptic cell adhesion, and detected new synaptic genes associated with ASD, suggesting that ASD could be the consequence of an alteration in the homeostasis of the





synaptic currents in specific regions of the brain.

In general, the genes that have been reported to be associated with ASD are all involved in coding for neuronal organization and neuronal migration. Errors in these genes are likely to be responsible for the dysregulation of brain growth seen in autism in the first few years of life. Neural overgrowth and/or malfunctioning neuronal pruning are reflected in the increase in brain size specifically during preschool years, which has been demonstrated by head circumference measurements and by structural brain imaging. This increase seems peculiar to autism.

Though twin and family studies have been consistent in indicating that autism has a very high heritability (circa 90%), it has been proved difficult to find the specific genes responsible for ASD. In addition to the likelihood of genetic heterogeneity and of very small effects of individual genes, the explanation may lie in synergistic effects among genes or in gene-environment correlations and interactions.

ENVIRONMENTAL RISK FACTORS FOR ASD

The raising number of persons diagnosed with an ASD across the world can have several different reasons (enlarged diagnostic criteria, earlier and more extensive diagnosis, trend to make a diagnosis which is likely to ensure more support). While actually the occurrence of an epidemic of Autism has not been proved, the evidence of the multi-factorial nature of autism spectrum disorders (ASD) means that some environmental factors are likely to be implicated in causation.

Historical studies on prenatal exposure to congenital rubella and phenylketonuria, as well as the more recent studies on prenatal exposures to valproic acid, thalidomide and pesticides, and new studies on circulating maternal antibodies, have suggested a risk association with ASD in offspring.

Abnormalities of the immune system in a subset of mothers of children with autism have been found. Circulating antibodies anti-foetal brain cells have been found in a proportion of mothers of children with autism. The inoculation of these human antibodies in pregnant monkeys has been demonstrated to lead to a nonhuman primate model of autism in offspring.

Current findings related to environmental risk factors for autism point to pre-natal exposure to a range of environmental agents. These findings could help to identify biologic diagnostic criteria and early prevention in a sub-population of children at risk of developing ASD. On the contrary, though all the environmental agents potentially enhancing the risk for ASD have not been identified. Maternal immune factors seem to be involved in enhancing the risk for developing autism in the offspring. However, restrictive diets or food supplements administered to children with ASD are unlikely to have some efficacy in curing ASD, as the condition develops in the pre-natal life.

Prospective longitudinal studies of very large samples starting during pregnancy, and including good biological measures, are needed to test the environmental factors exposures which are likely to enhance the risk of developing ASD. The MARBLE study is one of such investigation.

MMR AND THIMEROSAL

Claims have been made that either the measles, mumps, rubella (MMR) vaccine or thimerosal (a mercury preservative used in some vaccines), or both, were responsible for an epidemic of autism. Research findings using a range of strategies have been consistently negative regarding both these possibilities.

REGRESSION

Sibling prospective studies found that 86.4 percent of the infants who later develop autism show a clear decline in social communication after 12 months. This differs from previous reports, based



on which the researchers expected to see regression in only a small proportion of the children, and suggests regression occurs in the majority, if not all, children with ASD.

Epidemiological research suggests that regression is much more common in autism than in other developmental disorders. This process is peculiar of ASD and is likely to reflect some neurological process to be investigated in the future.



EPILEPSY

Follow-up studies have shown that autism is associated with epilepsy that is particularly likely to have an onset in adolescence or early adult life. Once again, the unusual age of onset is peculiar to autism, and must have a neuropathological meaning to be investigated.

MENTAL RETARDATION

Family studies have shown no association of ASD with mental retardation in families. Mental retardation is currently recognised

to be an expression of the severity of the core deficits of ASD, i.e. a consequence of autism, which is likely to be prevented by addressing social and communication symptoms. In fact, early intensive treatments focusing on the core symptoms of autism have shown to impact intellectual disability in children with ASD.

SOCIAL / COGNITIVE FUNCTIONING

There are well replicated findings on impairments in 'theory of mind', joint attention, imitation and action understanding. Progress has come particularly from a greater use of experimental designs, the application of eye-tracking methodology, the use of functional brain imaging, and

the 'baby-sibling' prospective studies.

Studies on mirror neurons have detected some possible mechanism leading to the social deficit in ASD. Mirror neurons become active both when the individual executes a specific motor act and when it observes another individual doing a similar act, but only if the observed motor act is part of a specific motor chain (e.g. grasping-to-eating). This mechanism allows the observer to understand the individual's intention.

Children with autism fail to recognize the why of an action. This impairment, which is reflected in a lower activation of mirror neurons, make children with autism to lack experiential understanding of others, relying in their behavior on external factors.

According to the E-S (Empathizing-Systemizing) theory, autism entails below average empathy alongside intact or even superior systemizing. Empathy is the drive to identify another person's mental state. Systemizing is the drive to analyse or build a system. Psychological theories can give rise to practical interventions, for example, in teaching emotion recognition to improve empathy.

Recent studies suggest 2- and 4-year-old children with ASD to show a restricted scanning pattern in response to novel static faces, which appears to hamper their ability to effectively encode facial identity information. Moreover, attention to



key facial features appears to decline from 2 to 4 years, which suggests that face processing, might become more abnormal with age. This deficit has been shown to affect learning. A dissociation between sensitivity to referential cues and emotional cues and a causal relationship between difficulties in face processing and action understanding in this population have been demonstrated.

DIAGNOSTIC CRITERIA

Leo Kanner's observations of the particular deficits in affect and social relations as well as the maintenance of sameness in a small group of children 50 years ago have remained the central components of diagnostic criteria for autism but priorities and additional characteristics have varied over the years.

DSM-V, the new forthcoming classification by APA (American Psychiatry Association) will focus on defining appropriate criteria across developmental, chronological and language levels that are easily interpretable by clinicians and that accurately reflect the similarities within the spectrum while differentiating it from other disorders.

There is a consensus that the distinction between impaired social reciprocity and impaired communication is artificial, although uncertainty then arises on abnormal language features (such as pronominal reversal or delayed echolalia). The evidence suggests that repetitive stereotyped behaviours are separate; although uncertainty remains on whether there should be a split between 'insistence on sameness' and 'repetitive sensorimotor behaviours'.

The concept of Asperger syndrome was useful in indicating that autism can develop in individuals who gain speech at a normal age. Nevertheless, the sub classification of autism spectrum disorders

has proved problematic and lacking in adequate empirical validation. The DSM-V working parties have argued that it is time to dispense with all the sub classification and have just one diagnosis of autism spectrum disorder.

There will need to be some means of identifying disintegrative disorders - not because we are sure that they are different but, rather, so that the possibility can be investigated.

Both epidemiological and twin study findings have shown that autism extends well beyond the traditional highly disabling diagnostic concept to include a mixture of social and communicative impairments that are similar to, but milder than, those found in autism. These have been termed 'a broader phenotype'. The phenomenon raises the query of how the broader phenotype becomes transformed into autism.

PRODROMAL FEATURES IN INFANCY

Many studies have shown that the siblings of a child with autism have a much increased risk of developing autism.

Awareness that this is so has led to multiple international 'baby sibling' studies in which siblings are studied prospectively from early in life to identify and delineate precursors of autism. Diagnostic markers which differentiate children with ASD from their typically-developing peers during the first 6 months of life have been explored. One path toward possible early diagnosis of autism is to use eye-tracking studies to see and measure social engagement. How often, for example, does an infant look at the face of an interviewer? Some children have abnormalities in visual scanning in normal, social settings. Such studies could reveal vulnerabilities for autism in the first months of life, a year or two before the disease begins to become apparent. They might also help predict the degree of impairment and social disengagement that at-risk children can expect.

LACK OF MARKED RESPONSE TO MEDICATION

Numerous studies have documented that psychotropic medication is of some value for associated problems, but autism stands out from almost all other psychiatric disorders in showing no marked benefits of medication on core symptoms (such as impaired social reciprocity and social communication). Why? One possible implication is that the basic deficit does not involve neurotransmitters; if not, what does it involve?



ADULT FUNCTIONING

Long-term follow-up studies have shown the varied outcomes of autism, with a surprisingly high proportion of individuals with a performance IQ in the normal range remaining severely impaired in their psychosocial functioning. Though the same dramatic effects of early treatments cannot be expected in adults, the demonstration of the brain plasticity and impact of learning on brain development strengthen the need for providing active support and proper services to all persons with ASD, in order to foster the best individual development and to prevent exclusion and dependency, in a rights-based perspective of ASD and regardless the age and severity of the affected person.

AGEING AND AUTISM

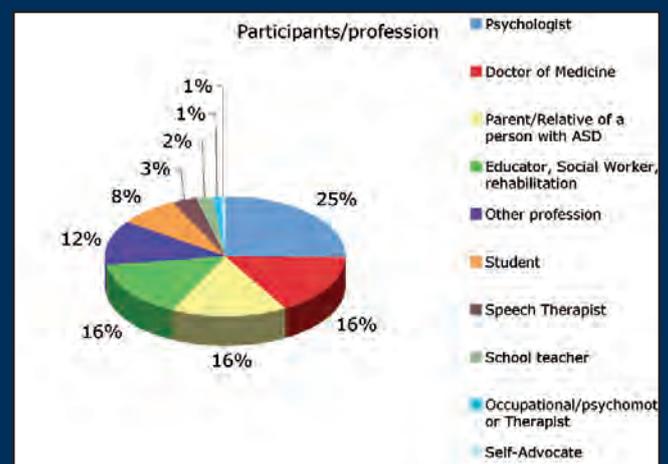
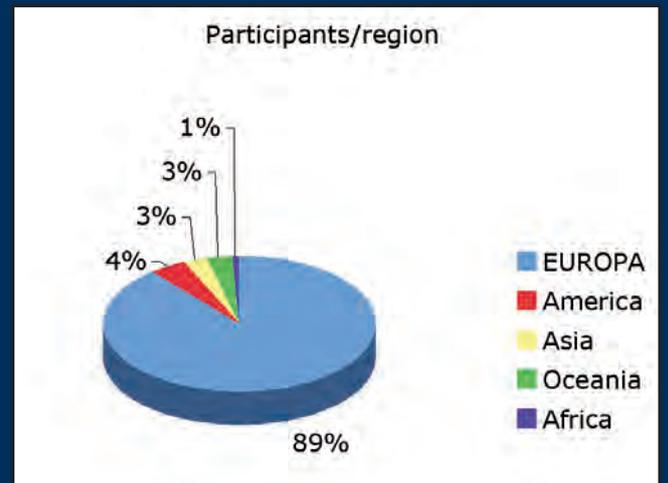
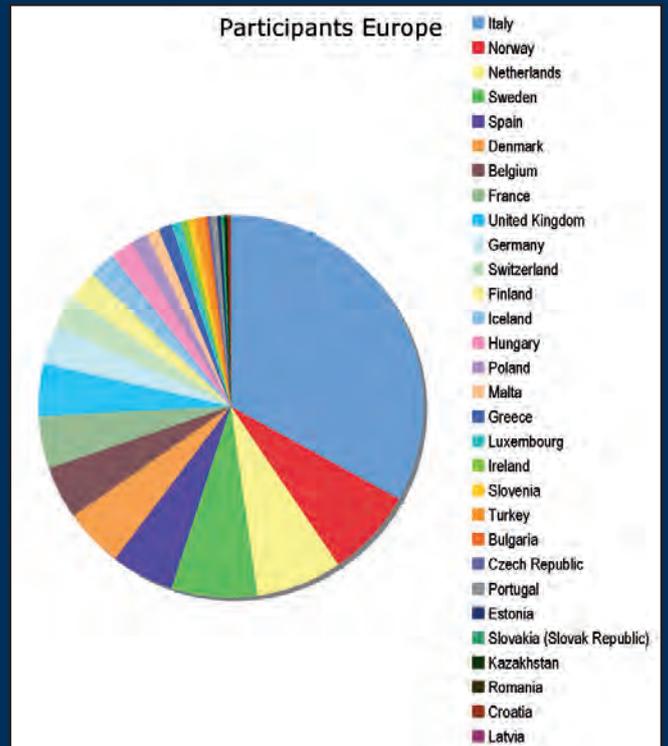
None of the studies into adult life in ASD, to date, involve individuals much beyond the age of 30 or 40 years. This is despite the fact that the percentage of adults in the general population who are over 60 now outstrips the proportion under 16 for the first time, and this is, in fact, the fastest growing age group. The challenges of an aging population are slowly being recognized by governments, but the potential problems in relation to people with developmental disorders, such as autism, has hardly even been considered.

PSYCHOLOGICAL TREATMENTS

Recent efficacy studies suggest that very intense, very early behavioural treatment can lead to 'recovery'. That such treatment can bring worthwhile benefits is not in doubt. Whether or not there is complete recovery and whether this recovery maintains in the long term is much less certain.

EVIDENCE BASED TREATMENTS

Research findings on autism and related conditions have implications for intervention programs. Scientific evidence regarding behavioural, pharmacological, complementary and alternative treatments should inform parents and teachers decisions about treatments, Scientific knowledge should be applied to intervention programmes which are practically helpful while remaining scientifically based.



V international art exhibition of people with autism «Touches of Autism»

Venue:

«The Ciminiera», Catania,
8 to 10 October 2010

The inauguration of the exhibition took place on October 8, 140 works were shown in the exhibition area.

Speakers at the opening ceremony were:

Simona Palacios,
President of Autism Burgos

Evelyne Friedel,
President of Autism-Europe

Laura Esteban,
Professor of the Painting Workshop
Autismo Burgos

During the opening act the tale «The Silence of Camilo», by M^a Jesús Jabato, was also narrated, together with a projection of the illustrations of the book. It tells the story of a young man with autism who just had a brother. The book is illustrated by Laura Esteban.

The awards «Artismos», were bestowed on artists who produced the winning works, according to the decision of the jury that met in Burgos on June 8th 2010:

1st Prize :

Merceron Perrine of Personimages,
France

2nd Prize :

Yolanda Manrique Fundacion Menela

3rd Prize :

Mary Sacaluga of Pauta

Special mention :

Edorta Gomez of Autismo Burgos

Price of the public

awarded to the work of **Rosa Dual** of Gautena "Two friends", during the Catania Exhibition.

The International Art Exhibition has been designed as an itinerant show, so other entities from different countries may hold it. This time the exhibition will be displayed in the Cortes de Castilla y León (Valladolid) from 3rd to 20th December. The exhibition will coincide with International Day of People with Disability (3rd December).

From 4th to 16th January 2011, the Exhibition will be displayed in Burgos (Monasterio San Juan).



Burgos' Stand

Autismo Burgos had a stand during the conference which showed the latest publications of the Association and learned about the history of international exhibitions and artistic expression in people with autism.

The catalogue of the IV International Exhibition «Dialogues in Colour» was distributed. This edition was held in Oslo in 2007, during the previous Autism Europe's Congress.



Yolanda Manrique,
Fundacion Menela



Mary Sacaluga,
Pauta



Edorta Gomez,
Autismo Burgos



Rosa Dual de Gautena
Prize of the Public



European Days of Autism: A future for Autism

The European Days of Autism were celebrated at the beginning of October 2010 together with the Autism-Europe IX International Congress in Catania entitled "A Future for Autism". On that occasion, Autism-Europe raised awareness about the fact that nowadays persons with autism and their families very often lack the support they need to live a dignified life. As the population is ageing, persons with autism and their families are faced with very complex difficulties and a lack of adapted services. Action is therefore required to ensure that persons with ASD benefit from the same opportunities as the rest of the European citizens.

Autism is a significant lifelong disability, due to multiple medical causes, interfering with the normal development and functioning of the brain, identifiable in very early childhood. Autism deeply affects the way the person communicates and relates with his or her environment. It is characterized by a triad of symptoms: impairments in social interaction; impairments in communication; and restricted interests and repetitive behavior.

Autism can affect any family, regardless of ethnic or social class, and it is four times more frequent in males than in females.

There is now converging evidence that, using current diagnostic criteria, many more individuals, in many different countries are being diagnosed with Autistic Spectrum Disorders (ASD). Rigorous surveys from North America found that about 1 in 150 8-year-old children in multiple areas of the United States had an ASD. Epidemiological studies from Europe point to a similar figure among children (0,9 per 150, or 60 per 10.000). Autism is therefore not a rare condition. The Member States of the European Union and the Council of Europe should therefore pay a particular attention to autism considering the high prevalence of this disability.

At the occasion of the European Days of Autism and of AE IX International Congress in Catania, the objective is to raise awareness of the rights of persons with ASD and the necessity of providing them with life-long quality support services. Nowadays there is indeed a dramatic shortage of adapted, evidence-based services for persons with ASD throughout their lives.

Autism does not only affect children but also adults who often do not benefit from the adequate support to live an independent life. People with ASD, as the rest of the European population, grow older which implies the need to provide adapted services and care, in particular after their families' death or breakdown.



(Suite de la page 9)

Recent surveys led in the UK show that Adults with autism are often unable to access the right support, and consequently often become dependent on their families. 61% of adults with autism rely on their families for financial support, over 40% live at home with their parents. Most provision for adults with ASD comes from families, as a matter of fact, but when family care is not available any more an alternative support must be provided. The provisions for elderly persons with ASD should not be simply a “parking”, but ensure them to be respected citizens and participate in community activities as anyone else.

ASD features do not necessarily improve with age, mainly if persons with ASD did not have access to proper education and habilitation programmes. On the contrary, elderly persons with ASD can show more complex needs in terms of health care and support. As a consequence, ageing of persons with ASD implies not only the need for a life-long qualified support, but also enhanced intensity of the care in their elderly age.

In contrast, many elderly persons with ASD or other complex dependency needs disabilities are placed in large, segregating institutions, as well as young adults with ASD or other complex dependency needs disabilities, whose families are not likely to be able to ensure fundamental rights to life-long, effective education, habilitation and inclusion. To their detriment, neither the community nor the policy makers in many cases are ready to accept to support adequately long-term dependency and to provide the financial and professional resources needed. The issue of ageing of persons with ASD opens therefore a wider debate on the de-institutionalization process and its meaning for persons with ASD.

The needs of ageing people with autism are the same as those of other ageing people: economic, social, residential and affective, but aggravated by the neurological, physiological and psychological factors linked to their specific condition.

Autism-Europe would like to highlight and support the recent initiatives of several European institutions to raise awareness about the challenges of an ageing population. In particular, on 8 July 2009 the European Council's Committee of Ministers addressed a recommendation on ageing and persons with disabilities to Member States. It should be underlined that this recommendation makes a clear distinction between “ageing people with disabilities” and “older people with disabilities”. The first group refers to people who grow old having experienced a disability for much of their lives, sometimes from birth. For the second group, disability is first experienced at a relatively advanced age. The broad outlines of the Council of Europe new recommendation aim at promoting autonomy and an independent life of ageing people with disabilities ; enhancing the quality of services and ensuring equal access to those services.

During the opening ceremony of AE IX International Congress, Evelyne Friedel, President of Autism Europe, reminded that the Council of Europe indicates that ageing of people with disabilities, particularly of those requiring more intensive support, compels Member States to adopt innovative approaches. This is particularly relevant for persons with ASD due to their complex needs. On the occasion of Autism-Europe's IX International Congress, she welcomed the recent innovations in the field of evidence-based treatments and interventions for persons with ASD. She also calls on Member States to take concrete actions to improve the conditions of life for persons with autism - including elderly people - and to cooperate at European and International level to promote the exchange of information and best practices.

Tribute to Gilbert Huyberechts Autism-Europe's President from 1988 to 2000

Autism-Europe was deeply saddened to learn of Gilbert Huyberechts's death on 17 December in Luxembourg. We would like to express our sincere sympathies to the family and all Gilbert's friends at this most difficult time.

Gilbert was the President of Autism-Europe from 1988 to 2000. He significantly contributed to raise awareness of the condition of persons with complex dependency needs disabilities and unable to represent themselves.

Under his Presidency, Autism-Europe grew and was recognized as a unitary and reliable movement advocating for the rights of the most excluded persons with disability, by the disability movement as well as by the European Institutions. He actively contributed to the creation and strengthening of the European Disability Forum (EDF), of which he was the Vice-President and the Treasurer. He also took part in the creation of the Social Platform of Social NGOs.

In Luxembourg, he founded one of the first examples of alternative community-based services to institutions in Europe for persons with severe autism in need of high level of support. It ensured a dignified life in a friendly and respectful environment for many adults with autism who used to live segregated in a psychiatric hospital.

Autism-Europe Vice President and EDF Vice President Donata Vivanti recalls: "I met Gilbert in 1994 at a CA meeting of Autism-Europe. His strong commitment and sincere willingness to advance the cause of persons with autism convinced me to engage more and more in the advocacy work at European level. I learned from Gilbert everything I know about the respect for diversity, the pursuit of equal opportunities for all and the rights based approach to autism and disability. With him I am losing a teacher, a guide and a dear friend. I will miss him awfully, but he will always live in our hearts".

Isabel Cottinelli, member of AE CA and former vice-President considers that "Gilbert was the soul of Autism-Europe. I had the pleasure of working with him for 18 years and was a witness of his spirit of mission. His strength and dedication were contagious to everyone who was linked to the cause of the persons with Autism."

Claude Schmit, member of AE Executive Committee and Council of Administration, shares remembrances "Gilbert dedicated his life to

the cause of autism. In Luxembourg, he was the first parent to lobby actively for autism and consequently was a founding member of the first association that dealt with autism. Already in 1992 when I met him for the first time, he spoke about his vision for our country: creating a parents foundation that would defend the rights of people with autism and initiate community based services to ensure that they can lead their life in dignity. Thanks to him, this vision became reality. He always spoke about his second vision: Autism Europe and a common fight of all the parents associations in Europe. His immense knowledge and outstanding energy were impressive."

Paul Tréhin, former member of AE Executive Committee and Council of Administration recalls that "Gilbert's dedication to the cause of autism defence never failed. He had the formidable vision to bring autism advocacy out of the closet and made it a cause shared by all European organisations starting with EDF. Gilbert extended autism visibility even further when he got Autism-Europe directly involved in the creation of the European Social Platform. So now many organisations have heard about autism from people who were involved in autism and have now at least some knowledge about our fight for our children, and some came to realise that they too had similar problems in their hands so our unity would benefit all."

Bruno Gaurier, member of EDF remembers: "He was always searching peace amongst people, amongst opinions, as a true democrat, in full respect of the floor given to every/anybody, above all those who could not directly speak and advocate for themselves."

Josée van Remoortel, former President of Mental Health Europe also recalls "Gilbert was a quiet gentleman with an outstanding knowledge always listening and trying to make positive responses. His engagement towards the disability movement will be remembered with great gratitude by everyone who had the chance to have known him."

EDF President, Yannis Vardakastanis remembers him as a great friend and valuable comrade in the long struggle to build in Europe a strong, empowered and united disability movement: "I will never forget the world we built together in the working groups in 1995-96 that drafted the first constitution of the European Disability Forum. Gilbert, together with Bas Treffers, another colleague, was the one of the founding fathers of EDF. He will never be forgotten by his friends and colleagues in the disability movement all over Europe. The best way to honor and remember Gilbert is to continue the fight to protect and promote the rights of persons with disabilities and more specifically to increase the presence and understanding of disability, people with complex dependency needs within the disability movement and within civil society. "



Project

for inclusion

Lynn at Senedd launch



The Deis-Cyfle! Project:

Developing skills for employment and educational integration.

Lynn Plimley, Project manager

1. Background of partners and history of Project

The Deis-Cyfle! ('opportunity' translated into Gaelic and Cymraeg) Project - Developing Skills for Employment and Educational Integration - focuses on individuals with autism spectrum disorders (ASD). Against a backdrop of rising incidence in the diagnosed cases of ASD world-wide (1:100, Baird et al. 2006), there has been a large demand in awareness and skills training for a wide variety of practitioners and other groups. The medical diagnosis of ASD is assessed upon the presence of significant impairments in these three areas:

- Communication
- Social Interaction
- Flexibility of thought and behaviour

These impairments are often accompanied by reported differences in the way in which sensory information is processed.

Evidence of these three impairments (Triad of Impairments) needs to have been present in the early developing child before the age of 3 years for a diagnosis to be made by a multi-disciplinary team. Not all individuals with ASD are assessed in early childhood and a diagnosis can be made at any stage throughout the lifespan. The nature and manifestation of the lifelong condition of ASD can challenge services and practitioners to examine their professional practices and belief systems.

Many individuals with ASD can be, and have been, highly successful in their chosen careers and live independently in their own communities. Other people with ASD may not grow up to lead completely independent lives and there exists a paucity of services world-wide to enable them to reach their potential. It is recognised that a variety of support structures and planned opportunities need to be established in order for individuals with ASD to achieve their potential post school. However, levels of understanding and awareness about the condition of ASD amongst typical post school providers (careers, higher and further education; leisure services and employers) are often minimal and post school providers are often misinformed. The Project's main activities are constructed around improving this in a geographical area prescribed by the European Regional Development Fund. Autism Cymru as the lead partner has built up a strategic and political profile since its creation in 2001.

The Irish Society for Autism has built up a portfolio of services for people with ASD and has worked to serve parents and families of people on the spectrum since 1963.

It has developed a strong and experienced workforce in services for adults with ASD for over 25 years, and its model of service provision has been successfully replicated throughout other countries in Europe. Autism Cymru possesses an expertise in developing and offering training to a wide range of practitioners nationally. The partnership between the 2 charities will build upon the strong foundation of the 5 years of Welsh experience of running 'the Inclusive schools and ASD Whole School Research and Training Project'. Over 400 schools have been trained via this package by Autism Cymru.

The aim of this cross border partnership project between 2 national charities for ASD will be to develop a raft of training and self evaluation mechanisms that can form a basis for improving/increasing employability of people with ASD. The co-operation between the partners will bring together their complementary skills of training, knowledge and practice expertise to enhance the secondary school experiences of many with ASD and aim for an achievable educational and employment future for them.

The synergy of professional expertise, knowledge, experience and understanding of both partners during the 3 year lifespan of the Project will extend to further develop tiered training opportunities for practitioners working with young people and



Pat Matthews at Senedd launch



Prof. M. Fitzgerald at the project launch in Dublin



Project Coordinator Tara from the Irish Society and Dennis Sexton

adults with ASD. This, in turn, will positively impact upon the secondary school experience of youngsters with ASD, enable them to make realistic life choices and continue on into post school education and employment routes.

2. European Regional Development Funding

Both charities submitted a proposal for joint funding from the Ireland Wales Programme 2007 - 2013 (INTERREG IV A), with a commitment to matched in kind funding, in September 2008. The INTERREG programme seeks to develop cross border cooperation in the region of economic, social and technological issues and to:

- Contribute to its greater competitiveness and sustainable development
- Improve its overall economic, environmental and social well-being
- Achieve a more cohesive, balanced and sustainable development of the Ireland Wales cooperation area, and thus contribute to the overall competitiveness of the Community territory in a globalised world' - (www.irelandwales.ie)

With the objectives based on the Lisbon agenda (2000), the INTERREG programme also seeks to:

- Develop the knowledge, research & development/innovation and entrepreneurial base of the cross border region's economy with a view to boosting the region's growth and competitiveness
- Enhance the capacity of the cross border region by providing targeted interventions to develop the skills and abilities of the population and the workforce, with a view to providing greater levels of employment, and to foster competitiveness.

This is broken down into two separate but allied themes:

- Theme 1 - Innovation and competitiveness;
- Theme 2 - Skills for competitiveness and employment integration.

The Deis Cyfle! Project fulfils the second of these themes by being based on the develop-

ment of close cross-border collaborations and partnerships with a range of statutory and independent sector agencies and with stakeholder engagement. It aims to establish an innovative approach to the acquisition of knowledge and skills needed to ensure that the several thousand people with ASD living in the defined Project areas are provided with the best grounding and opportunities to enter the employment market.

Separately or working together, both charities would be unable to fulfil these objectives within the constraints of their budgets and other funding. By submitting the proposal to the INTERREG programme, with cautious but achievable aims and based upon the success of an established training programme, the partners were seeking to extend the scope and effectiveness of awareness raising materials. The rigour of the INTERREG application process helped to focus and develop ideas and will enable us to meet our yearly targets. The access to the support of the dedicated Wales European Funding Office and South Eastern Regional Authority staff will also ensure that we keep up with the documentation and paper trails that are a necessity to securing European funding. The funding will enable both partners to work in new ways and form a cohesive Wales-Ireland approach to developing the knowledge, skills and expertise of potential post school providers, thus ensuring a wider range of employment, leisure and study opportunities for individuals with ASD.

3. The Project aims

The Deis Cyfle! Project will build upon the highly successful bi-lingual training package that Autism Cymru has been running in local authorities since 2005. Deis Cyfle! intends to extend the scope and relevance of these materials to include the issues that commonly arise in secondary schools, work experience provision, careers, leisure, employment and further and higher education establishments.

Between 2009 and 2012, the Project aims to increase employability and provide greater opportunities for school leavers with Autism Spectrum Disorder (ASD) by providing a greater knowledge and understanding of Autism. This will be achieved, through the collaboration of The Irish Society for Autism

and Autism Cymru, by developing relevant 3-day training packages and self evaluation tools. Bespoke training materials will be developed for delivery to a range of practitioners and the training will be accredited by University of Wales, Newport. These materials will be tailored for secondary teachers, leisure and higher/further education providers and employers of people with ASD. Ultimately, the project will enable individuals with ASD to achieve their potential in the world of jobs, leisure and education.

4. Typical difficulties of those with ASD in later school years and entering adulthood

Young people with ASD will have some differences from their peers and some of these differences will often persist through their lives. For instance, issues concerning:

- Eating
- Sleeping
- Changes and transitions
- Understanding what is needed in social situations
- Making choices
- Having a repertoire of socially appropriate behaviours
- Understanding verbal and non-verbal communications
- Developing friendships with others
- Dealing with anxiety and stress

may feature, to a greater or lesser extent, for their lifetime. Sensory differences can also accompany ASD and young people with ASD may experience sensory stimulation (smell, touch, taste, hearing, sight and whole body sensations) as overwhelming, particularly at times of stress.

Children entering a new secondary school may take a long time to adjust to the many changes that the new setting has, compared to their primary school. Secondary schools tend to be much larger and deal with a larger population of people, not just pupils but also staff groups. They are accommodated in large buildings and their timetables will be different, with the expectation that pupils will be organised and able to navigate their way around. Hence, transition to a new school will need planning



and preparation and this is a pattern that may need repeating for subsequent changes, such as residential trips; outings; examinations; vocational subjects involving practical activities and also for physical development during adolescence and puberty. The whole process of physically maturing with accompanying hormonal changes will often be a trying time for young people with ASD (and their families and teachers).

The outcome of a secondary school life will involve young people with ASD making choices of subjects for examinations/ accreditation; anticipating a life beyond that of school and what they want to do; choosing a future path – college; university; employment; a varied lifestyle, including leisure pursuits; a major transition in leaving school and more expectations of independence.

An understanding of the nature and extent of these differences is going to impact upon everyone who comes into contact with the young person with ASD. The development of this knowledge and understanding will be critical to the whole school staff and subject specialist teachers, the local community service providers (transport, sports centres, youth clubs, youth organisations, shops, churches, libraries, and cinemas/theatres), careers advisers, potential employers and staff of colleges and universities, to ensure that the young people with ASD have the same opportunities as their peers. .

5. Activities and tasks of Project completed in first year

For our first year (May 2009- April 2010), we have been focussed on our consultation, training and awareness raising in secondary schools in Gwynedd and Ynys Môn in Wales and Dublin in Ireland.

In Ireland, several training seminars were attended around the country, for example at the National University of Ireland, where discussions concentrated on transitioning students with special educational needs.

In Wales, authority representatives, parents, support agencies, teachers, health and social services received an open invitation to a free ASD information and awareness raising seminar which took place in Caernarfon at the end of November 2009. The Project was publicised in Ireland via attendance at some key events to distribute information and Deis Cyfle! leaflets.

During February and March 2010, three free one day training sessions (2 in North Wales and 1 in Dublin) were organised for those who work directly with supporting young people with ASD in secondary schools and other provisions.

Feedback from these events (see later) will help to refine and develop more relevant training packages for this particular target audience, which will then be trialled afresh during the second year of the Project.

Both charities have been collecting and assembling data which will help pinpoint where young people with ASD are placed

and yield information on their likely routes post school, as well as what their local opportunities for education/employment are.

These Project activities will be repeated each year of the three years in different geographical areas and over time will also include leisure and careers professionals, potential employers and employment schemes, as well as colleges of further education and universities.

The Project has also been officially launched at the European Public Information Centre, Dublin in March 2010 and at the Welsh Assembly Government Senedd in May 2010.

INTERREG is a European Commission initiative financed by the ERDF (European Regional Development Fund).

The aim of this programme is to strengthen economic and social cohesion in the European Union through cross-border (part A), transnational (part B) and interregional cooperation (part C).

Currently we are in the fourth programming period called INTERREG IV. It covers the period 2007-2013.

Implementation of Pilot Programs for the Social Integration and Vocational Rehabilitation of Students with Autism in Greece (2006-2008)

This article will present a short report of a Pilot Project funded by the European Community and the Greek Ministry of Education, Continuing Education and Religious Affairs (EPEAEK II, Measure 1.1. "Improvement of Integration Contexts in the Educational System for Persons with Special Needs", Category of Acts 1.1.1 "Upgrading and Expansion of the Education for Persons with Disability", Act 114 "Education of Persons with Disability").

The social integration and vocational rehabilitation of persons with special educational needs in Greece has followed a slow and fragmentary course, due to lack of legislation and appropriate educational support. Specifically, it has been only a decade since persons with autism spectrum disorders (ASD) have been identified as separate category of students with special educational needs being eligible for special education support within the general education system (Public Law 2817/2000). This pilot Project was initiated with the aim to serve the purpose of investigating the prerequisites, positive outcomes and obstacles of social integration and vocational rehabilitation for students with ASD.

Aims of the Project

This Pilot Project had dual purpose: a) the implementation of programs for the social integration of students with ASD, attending special schools into mainstream education, and b) the development of transition programs for adolescents with ASD to vocational settings in the community.

Professionals Participants

Four groups of professionals (n= 92) from three cities (Thessaloniki, Serres, Volos) in the North and Central Region of Greece participated in this Project:

- 23 special education teachers, 2 psychologists, 5 paraprofessionals from elementary special education units
- 14 general education teachers
- 32 special education teachers, 5 psychologists and 1 paraprofessional from secondary special education units, and
- 10 employers.

Persons with ASD and typical development

The following groups of children/adolescents took part:

- a - 21 children with ASD were attending elementary special schools
- b - 14 adolescents with ASD were attending pre-vocational education units, and
- c - 318 typically developing children (2nd to 6th grade) came from 15 classes in seven general education public schools.

Schools and work sites

All participants were recruited from and transitioned to:

- 6 special education schools
- 7 general education schools
- 3 secondary units for pre-vocational training for persons with special needs
- 1 technical special education unit, and
- 10 work sites (i.e. candle factory, sweet factory, ceramic workshop, supermarket, gardening centre, piggery, weaving workshop)

Team of Consultants

- 4 faculty members with expertise on special education, inclusion and IT
- 4 elementary special education teachers
- 2 secondary special education teachers
- 1 psychologist
- 1 psycho-educational therapist, and

Consultant on Structured Teaching: Dr Steve Love, Clinical Director of the Asheville TEACCH Center, NC, US.

Methodology

The Pilot Project included the following phases:

Phase 1: Initial training of participants and initial assessment

30 hrs of initial in-service training of all professionals, paraprofessionals and employees by the team of Consultants. This training was in group format (n=30) and took place within the units of participants. Trainees attended lectures and were given training material on current educa-

tional practices for implementing inclusion for students with ASD and transition to work sites.

Autism Awareness Program for students in general education, which included video presentation, Understanding Friends (Faherty, C.), the 6th Sense (Gray, 2002) and book reading (three storybooks on autism were written for Grades 1-6).

Formal assessment instruments for students with ASD: a) Psycho-educational assessment (using Psychoeducational Profile-3) and b) assessment of pre-vocational skills (using TEACCH Transition Assessment Profile). Besides, thorough informal assessment was applied for developing IEPs for all participants with ASD.

Phase 2 (September 2007 - June 2008): Implementation of the pilot integration programs

In this stage all teaching staff was supported through in-site training, which enabled them to apply primarily the Structured Teaching approach as well as other empirically validated educational approaches for school integration and transition to vocational settings. In the context of school integration, teachers and other staff developed educational material for students with ASD and their typically developing peers. All educational activities (n= 165) were implemented within the Flexible Time Zone (Evelikti Zoni), which is part of the National Curriculum and allows thematic instruction, group work and experiential learning. For the transition to vocational sites, teachers and other staff in secondary special education developed 48 visually structured activities/tasks (see photos). All educational activities and tasks can be downloaded from the website of the Project (<http://www.sed.uth.gr/autism>).

Evaluation of the project

Trainees reported that curriculum adaptations and structuring of work sites/tasks were made feasible through the constructive in-site training they received from the team of Consultants. Besides, teachers and students in general education considered useful the autism awareness program for the typical peers before the integration of students with ASD. Overall, this project has initiated the systematic implementation of school integration and transition to vocational sites following TEACCH principles in Greece through the successful collaboration of special education teachers, paraprofessionals, general education teachers and employers for the benefit of students with ASD.

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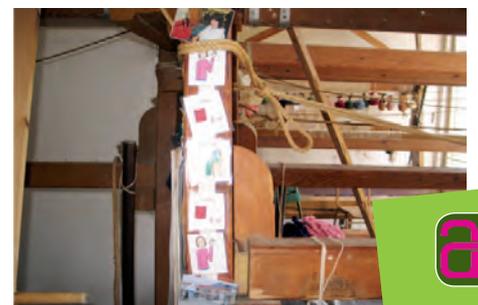
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Dept. of Special Education, University of Thessaly, Greece



Classroom task on road safety



Classroom task on food pyramid



Work system in the weaving workshop

Projects



On top of the Etna volcano

ACE Autism Connections Europe

Autism Connections Europe consortium's objective is to provide adults (18 years old and more) with autism spectrum disorder with the opportunity to enhance their communication and social skills, participate in online communities, travel to other countries (Slovenia, Italy, Great Britain and Estonia) and become active citizens by presenting and enforcing their rights.

The 2nd international ACE project conference on autism took place in Sicily.

The main topic of the conference was the usability of online social networks for persons with autism spectrum conditions.

Between October 8 and 11 2010, Catania, Sicily, hosted the IXth Autism Europe International Congress. Autism

Europe is also a partner of the international Autism Connections Europe (ACE) project and therefore the Congress also encompassed the second international ACE project conference. The conference included the presentation of the most recent global research on autism and hosted top experts in the field of autism studies. Ami Klin from Yale Child Study Center and Patricia Howlin from St. George's Hospital Medical School of London also presented their work and engaged in a fruitful debate with the ACE project participants.

The ACE project seminar was entitled 'Using online social networks as a tool for developing social skills of persons with autistic spectrum disorder [ASD]'. The ACE project was presented by Vesna Melanšek, president of Center for autism Slovenia and Janja Kranjc, psychologist in the Center for autism Slovenia and head of the ACE project. Marianne Kuzemtshenko presented a talk regarding the Estonian Autism Society and its role in the project while Liuba Lacoblev introduced the Romanian organisation to the audience. John Lawson, senior lecturer in psychology at Oxford Brooke's University, presented the current course of research in the ACE project scope. One partici-

part with Asperger from Romania also presented the project and the various activities, with an entertaining presentation. Maddalene Fiordelli from University in Lugano spoke of the topical findings of the research in use on Facebook and its influence on communications skills of persons with ASD. Participants with ASD also shared their opinion on the ACE project. As well as taking part in this session of the conference the participants shared important experiences, engaged with Sicilian culture, visited Mount Etna and engaged in a variety of other social activities.

The conference concluded with an open discussion between the ACE participants and two experts in the field of autism studies; Ami Klin and Patricia Howlin. Ami Klin is a researcher of ASD and Asperger syndrome and a professor of children psychology and psychiatry at Yale Child Study Center. He published five books and many articles from the field of his research and received numerous awards for his work. Patricia Howlin is a researcher at St. George's Hospital Medical School of London and has presented her work in numerous books studying autism and Asperger syndrome at children.

Autism Connections Europe – a participant’s experience

Mircea-Valer Paucă,
Romania (36 years, Asperger Syndrome)

On Oct. 8th-10th, 2010, in Catania, Italy has taken place the 2nd of the 4 planned international meetings of the participants of ACE Project (Autism Connections Europe). This meeting was planned as part of the 9th Congress of Autism Europe.

Young adults on the Autism spectrum from Slovenia (4), Estonia (6), Romania (4) and Britain (2) travelled together with parent activists, organizers, support specialists from their countries to meet together, exchange experiences and prove ways to improve social communication, from electronic means to face-to-face – the stated aim of the ACE project.

The focus was on the sub-conference dedicated to the ACE project, on Oct. 9th. Lead researchers John Lawson (Oxford, UK) and Maddalena Fiordelli (Lugano, Switzerland) presented the design of the research that happens within the ACE project. Starting from the importance of friendship in human beings, they proposed the social network service Facebook to start communication, followed by face-to-face meetings, as well as detailed questionnaires and measures to track changes in social communication and general well-being of participants. Parents’ leaders from each country also presented the structures, efforts and achievements of their national autism organizations.

I presented my personal perspective on the ACE Project so far, especially from the previous meeting in Ljubljana, Slovenia. I felt it first most as a complex test of practical living skills, initiative and the capacity to

adapt to changing environments. Our limited executive functions are rarely used as thoroughly in our simplified, partly supported lives - like ‘military maneuvers’ test armies better than basic training. I considered such peak efforts as ‘happy emergencies’ and warned of fatigue and confusion that surely follow.

For the meetings planned for 2011 (Oxford, UK and Tartu, Estonia) I consider worthwhile to take into account more realistically our practical capacities by less ‘tight’ scheduling of activities, more flexible possibilities to pursue special interests and research activities, more structured small group interaction, more time to rest and less of the frustrating ‘hurry then wait collectively’, which have been unavoidable so far. I would have been most interested to attend several of the scientific presentations in the main Autism Europe congress - unfortunately other activities planned for us overlapped in time and space. Other participants were likely less interested.

Facebook was useful to prepare and reduce initial anxiety of not-knowing, but the required diary was felt as a chore to many of us, needing repeated ‘prompting’ from organizers.

Tourism and the special interests of each of us are major motivators. The following day we were all glad to visit the unique Etna volcano and Lava museum. Social communication was indeed improved in our group, also noticeably the usable knowledge of English needed as common medium for such a diverse European group. Such meetings give extra motivation for everyone to improve!



ACE participants during a debate with Ami Klin and Patricia Howlin



ACE participants with Ami Klin and Patricia Howlin





2011

The European Year of Volunteering



2011 is the European Year of Volunteering which aims at highlighting the achievements of volunteers in Europe and their positive impact on society. More information about the European Year and its related activities can be found on the website: <http://europa.eu/volunteering/en/home2>

SPOSA and its cooperation with young European volunteers

It was pretty warm and sunny when we arrived in Slovakia in the beginning of September. We are Anja, Joanna and Hugo : three volunteers of the EVS-Program of the European Union

We decided to work for 12 months in an organisation in Bratislava called „Society for the Help of People with Autism” (S.P.O.S.A.). This organisation supports autistic children and their families.

When we arrived we had little information about this country and the tasks we were to perform with autistic children but we had a lot of enthusiasm. We have been working for two months within S.P.O.S.A. now, but we are still making new experiences every day while working with children. You can never predict how a child will behave. We find it very interesting to discover the diversity of the Autistic Spectrum and to see how children with autism react in specific situations and how each child is very different from another, even in a small group.

Our task in S.P.O.S.A. is to propose and elaborate therapies and activities to teach autistic children how to act in ordinary life. These activities are for example cooking, ironing, washing and cleaning but also language and music classes, art and game therapies and sewing courses. These therapies begin normally between 14.00 and 15.00, after school. The rest of the time, we are working on public relations, we help update the association's webpage and organise special events like the “Dragonfly Weekend” in October, aimed for the children and their families, and “St Nicolas” in December.

Here is a short introduction of each of us, our motivation to work with autistic children and what we have experienced in S.P.O.S.A.

Joanna (28, from Poland) – I have been travelling in Central Europe for three years now and I chose this project in Bratislava because I found it was a good opportunity



to make something meaningful – working in an interesting organisation. Why do I thing that my voluntary work is interesting? First of all because our main interest is to teach children with autism. Here we can let aside new technologies, forget our hectic lifestyle and everyday routine in order to concentrate on what is really important: having good relations with other people, reflect about what is important in life and contribute to change someone else's life.

Anja (26, from Germany) – I finished my studies as a teacher this year in Germany. Before starting to work in a school I took the chance to spend several months abroad within the framework of an EVS project in order to make new experiences such as working with autistic children. At the beginning I just knew that autism is a disability, but nothing about its different symptoms. So it's very interesting for me to see how the children behave and act differently, although they all have the same diagnosis. Autism is not well known in the

society. S.P.O.S.A.'s work consisting in taking care of autistic children and supporting their parents is therefore all the more important. And I hope to contribute usefully to this work.

Hugo (21, from France) – I left France after a few years at university because I had the feeling that these studies were not useful for my life. I choose the EVS to discover another European country and to come out of my routine. In France I worked with children and I found out that I liked this kind of work. I took the



chance to work with autistic children because I wanted to find out if I could also handle the work with children with disability. I hope that this experience will give me a perspective for my future and help me develop myself. I'm very glad that I can work with people from other countries.

We do hope to make good work here in Slovakia and to be a valuable support for S.P.O.S.A. and especially for the children and their parents. We are glad to have seized this opportunity and are looking forward to the next coming months.

parents. We are glad to have seized this opportunity and are looking forward to the next coming months.

What is a European Voluntary Service project?

The European Voluntary Service (EVS) was set up and is still supported by the European Commission. It enables young people (aged between 18 and 30) to carry out voluntary service for up to 12 months in a country other than their country of residence. It fosters solidarity among young people and is a true 'learning service'. Beyond benefiting local communities, volunteers learn new skills and languages and discover other cultures.

An EVS project can focus on a variety of themes and areas of intervention, such as culture, youth, sports, social care, cultural heritage, arts, civil protection, environment, development cooperation, etc.

For more information, please visit the following webpage: http://ec.europa.eu/youth/youth-in-action-programme/doc82_en.htm



The EU Disability Strategy 2010-2020: empowering persons with disabilities in Europe

On 15 November, Viviane Reding – EU Commissioner for Justice, Fundamental Rights and Citizenship - announced the adoption of a 10 year strategy which promotes equal opportunities for people with disabilities.

The new Disability Strategy 2010-2020 is designed to be the instrument of the EU to promote empowerment of people with disability. It is a key document especially since the Council's adoption of the decision for the conclusion of the UN Convention of the Rights of persons with disabilities (UNCRPD). The UNCRPD is a legally-binding international instrument to which the EU and its Member States are parties. It will soon apply throughout the EU. The UN Convention requires States Parties to protect and safeguard all human rights and fundamental freedoms of persons with disabilities.

The Strategy outlines how the EU and national governments can empower people with disabilities so they can enjoy their rights. It focuses especially on removing all obstacles and making all goods and services accessible, to create, according to Viviane Reding, "a truly barrier-free Europe for persons with disabilities by 2020". The Commission has identified eight main areas for action: Accessibility, Participation, Equality, Employment, Education and training, Social protection, Health, and External Action.

This Strategy identifies actions at EU level to supplement national ones, and it determines the mechanisms needed to implement the UN Convention at EU level, including inside the EU institutions. It also identifies the support needed for funding, research, awareness-raising, statistics and data collection.

Specific measures over the next decade range from the mutual recognition of national disability cards, the promotion of standardisation to a more targeted use of public procurement and state aid rules.

Here is a short review of the areas of action:

1 - Accessibility initiative: considering how to use standardisation, public procurement or state aid rules to make all goods and services accessible to people with disabilities while fostering an EU market for assistive devices ("European Accessibility Act");





2 - Participation: making sure that persons with disabilities and their families exercise their EU citizenship rights on an equal footing, for example through the mutual recognition of disability cards and related entitlements.

The European Commission also expressed the commitment to promote the transition from institutional to community-based care by using Structural Funds and the Rural Development Fund to support the development of community-based services and raising awareness of the situation of people with disabilities living in residential institutions, in particular children and elderly people. EU action will support national activities to reach this objective, including use of Structural Funds and the Rural Development Fund for training human resources and adapting social infrastructure, developing personal assistance funding schemes, promoting sound working conditions for professional carers and support for families and informal carers.

3 - Equality: this will involve using existing EU legislation to provide protection from discrimination, and implementing an active policy to combat discrimination and promote equal opportunities in EU policies. The Commission will also pay attention to the cumulative impact of discrimination that people with disabilities may experience on other grounds, such as nationality, age, race or ethnicity, sex, religion or belief, or sexual orientation.

4 - Employment: the Commission intends to improve knowledge of the employment situation of women and men with disabilities, identify challenges and propose remedies. It will pay particular attention to young people with disabilities in their transition from education to employment. It will address intra-job mobility on the open labour market and in sheltered workshops, through information exchange and mutual learning.

EU action will support and supplement national efforts to: analyse the labour market situation of people with disabilities; fight those disability benefit cultures and traps that discourage them from entering the labour market; help their integration in the labour market making use of the European Social Fund (ESF); develop active labour market policies; make workplaces more accessible; develop services for job placement, support structures and on-the-job training; promote use of the General Block Exemption Regulation 16 which allows the granting of state aid without prior notification to the Commission.

5 - Education and training: Access to mainstream education for children with severe disabilities is difficult and sometimes segregated. People with disabilities, in particular children, need to be integrated appropriately into the general education system and provided with individual support in the best interest of the child. With full respect for the responsibility of the Member States for the content of teaching and the organisation of education systems, the Commission will support the goal of inclusive, quality education and training under the Youth on the Move initiative. It will increase knowledge on levels of education and opportunities for people with disabilities, and increase their mobility by facilitating participation in the Lifelong Learning Programme.

EU action will support national efforts through ET 2020, the strategic framework for European cooperation in education and

training, to remove legal and organisational barriers for people with disabilities to general education and lifelong learning systems; provide timely support for inclusive education and personalised learning, and early identification of special needs; provide adequate training and support for professionals working at all levels of education and report on participation rates and outcomes.

6 - Social protection: In full respect of the competence of the Member States, the EU will support national measures to ensure the quality and sustainability of social protection systems for people with disabilities, notably through policy exchange and mutual learning.

7 - Health: The Commission will support policy developments for equal access to healthcare, including quality health and rehabilitation services designed for people with disabilities. It will pay specific attention to people with disabilities when implementing policies to tackle health inequalities.

EU action will support national measures to deliver accessible, non-discriminatory health services and facilities; promote awareness of disabilities in medical schools and in curricula for health-care professionals; provide adequate rehabilitation services; promote mental health services and the development of early intervention and needs assessment services.

8 - External action: Promote the rights of people with disabilities within the EU external action, including the enlargement process and development programmes.

Autism-Europe warmly welcomes the range of objectives and actions set out in this strategy that can truly benefit to persons with Autism across Europe. We therefore intend to actively take part in its implementation.

Autism-Europe would also like to support the European Disability Forum's call for further improvements of the Strategy. For compliance with the UNCRPD, we consider that a transversal revision of the European legislation would be necessary, and not only the review of the EU employment legislation. We would also like to emphasize the importance of the full participation of DPOs in the decision-making processes concerning issues relating to persons with disabilities. In that regard, the creation a State of the Union on disability could be a valuable instrument. The proposal is to hold a high-level meeting every two years with the President of the European Council, the President of the European Parliament, the President of the European Commission and the disability movement. It will examine the progress that has been made on the rights of persons with disabilities on an inter-institutional level. So far, President of the European Parliament, Jerzy Buzek, and the President of the European Council, Herman Van Rompuy, have expressed their support for this initiative.

For further information about the EU disability strategy, please see: http://ec.europa.eu/news/justice/101115_en.htm

The Right to Healthcare and Habilitation for Persons with ASD

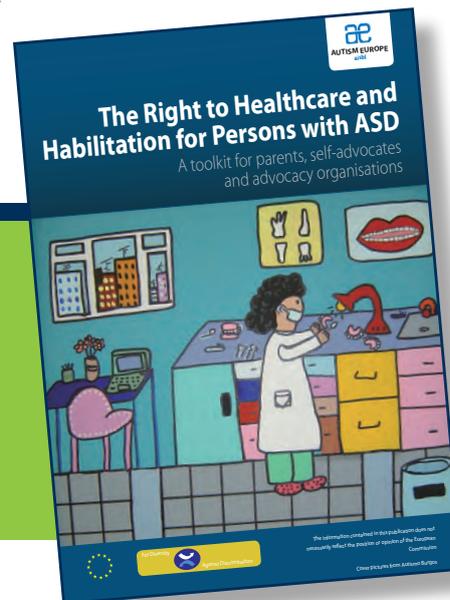
A toolkit for parents, self-advocates and advocacy organisations

This toolkit develops the previous documents of Autism-Europe on health issues, including the Position Papers “Autism and Health (2003) and “ A Rights-based, Evidence-based Approach to Autism Spectrum Disorders”, adopted by Autism-Europe, the European Society for Child and Adolescent Psychiatry – ESCAP - and the International Association of Child and Adolescent Psychiatry and Allied Professions – IACAPAP - at the VIII International Congress of Autism-Europe, Oslo, 2007, in the light of the new perspective to healthcare and rehabilitation enshrined in the UN Convention on the Rights of Persons with Disabilities (2007).

The present document is not intended to advise on how quality health and habilitation services for persons with ASD can be developed. It can, however, provide some ideas that can be useful to anyone wishing to advocate for the right to healthcare and habilitation of persons with Autism Spectrum Disorders, as well as to provide parents with some information that can help them to get the best possible care for their children with ASD.

Chapters 1 to 3 recall the main features of ASD, their consequences in the field of healthcare and habilitation and why the promotion of the rights to healthcare and habilitation are key issues for persons with ASD.

Chapter 4 takes you through the main legal instruments dealing with the right to healthcare at European and International level.



Chapter 4 then goes on to the right to healthcare and habilitation as stated in the UN Convention on the Rights of Persons with disabilities.

Chapter 5 analyses why and how healthcare should be considered a policy issue and discusses the role and the responsibilities of families and advocacy

organisations in developing policy actions in the field of best healthcare and habilitation.

Chapter 6 explains why the evidence-based approach is a key element of the right to health and habilitation of persons with ASD, and provides some suggestions aimed to help them and their parents in their choice of reliable intervention.

The toolkit has three annexes. The first reports case studies ensuing from the concrete experiences of the members of Autism-Europe in the field of healthcare provision and services. The second lists quality indicators of services for persons with ASD that were drafted by the members of the Council of Administration of Autism-Europe in 2007. The third is the strategy drafted by the Hungarian Association for People with Autism (AOSZ). The 5-years Strategy for Autism was commissioned by the Ministry of Social Affairs and Labour and drafted by experts as a recommendation under the supervision of the Hungarian Autistic Society. The Strategy aims to improve care for persons with ASD notably by developing specific services for persons with ASD and improving diagnosis, as well as access to education (including training for adults). One of the objectives is also to train staff to care for persons with ASD and to provide support for families. Another target is to develop employment opportunities for persons with ASD.

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INVITATION

TO AUTISM-EUROPE ANNUAL GENERAL ASSEMBLY Athens – Greece | April 16th, 2011

In accordance with the statutes of our organization, we are pleased to invite you to attend the Autism Europe Annual General Assembly, which will take place in Athens, on Saturday April 16th, 2011, in the afternoon, from 14.00-17.30:

- Presentation of the executive committee report
- Presentation of the Activity Report: 2010
- Presentation of the financial report: 2010
- Presentation of the Work Programme 2011

All the working documents related to the General Assembly will be e-mailed later to the registered participants.

Gala Dinner: Saturday April 16th, 2011 – 20h00

Please note that the AE Council of Administration meeting will also take place, in the morning, on Saturday April 16th and Sunday April 17th, 2011.

For more information, please contact Autism-Europe secretariat:
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