ACTIVITIES
- Annual General Assembly 2010 – Kassel
- World Autism Awareness Day across Europe
- IX international Congress 2010 – Catania

EMPLOYMENT AND INCLUSION OF PERSONS WITH ASD
- Vocational Training Programme and Job placement in Germany
- LEM cooperative

PROJECTS
- ACE connections Europe
- Participation of Autistic People in Europe – PAPE

NEW MEMBER
- APLA – Czech Republic

NEWS
- Panel of experts on ASD
Dear Friends,

Autism-Europe welcomes the fact that the specificity and complexity of the difficulties faced by persons with ASD to access employment have been acknowledged by the European Commission. Indeed, under the EC programme PROGRESS a call for proposals for new pilot projects which develop or test approaches to improve access to and retention in the open labour market for persons with ASD in a practical manner has been launched. It is of paramount importance, that they are followed-up by concrete policies to promote the employment of persons with ASD and other persons with disability with complex needs in Europe. The European Union is planning for the future, and persons with disability must not be forgotten.

“A Future for Autism” is precisely the title given to Autism-Europe’s forthcoming International Congress. As already announced it will deal with the radical innovation that has taken place in recent years in the field of ASD, covering the latest scientific advances as well as treatment, care services and education, etc. with the participation of the most renowned international experts. We hope to meet you at this occasion!

On the European scene, this period is also marked by major advancements. The new commissioner for Fundamental rights - Viviane Reding - has hailed the fact that the Charter for Fundamental rights is now included in the Treaty since the adoption of the Lisbon Treaty on 1st December 2009. She called for the creation of a “culture of fundamental rights” within all the Directorates General of the European Commission, which would impact on its work and policies. It is a positive development which should allow combating discrimination against persons with disabilities, an objective clearly mentioned in the Lisbon Treaty.

The European Commission has corollary announced that the UN Convention on the Rights of Persons with Disability will be deposited by the European Union as soon as a code of conduct for its implementation is adopted by the member states. It will allow the EU to take actions within its field of competences, even if all the member states have not ratified it yet.

In this respect, the European Commission has already committed itself to implement the UN Convention through concrete actions in various policy fields. These actions will be set out in a new European Disability Strategy 2010-2020 to be presented in autumn. It shall also be closely linked to the new general 10-year strategy for jobs and growth, the Strategy EU2020, adopted in June 2010 by the European leaders.

The Strategy EU2020 contains positive aspects such as the introduction of a Poverty reduction target. However there is no clear reference to disability. In order to put into action all the mentioned instruments, Autism-Europe therefore calls on disability to be mainstreamed in the various policy areas of the strategy by the European Commission and the Council. To this end, Autism-Europe strongly encourages you to lobby your national ministries responsible for social affairs, education, research and innovation that are currently drafting national programmes to meet the target of Europe 2020 strategy.

Thanks a lot for your cooperation and support,

Evelyne Friedel
President of Autism-Europe

Aurélie Baranger
Director
Annual General Assembly and Council of Administration meetings
5th & 6th June - Kassel - Germany

On 5th and 6th June, Autism-Europe held its Annual General Assembly and Council of Administration meetings in Kassel, Germany at the occasion of the 40th Anniversary of Autismus-Deutschland.

On Friday 4th, participants had the opportunity to visit a Therapy Centre and to discuss the situation regarding care for people with ASD in Germany with the director. They also visited the Documenta-Halle in Kassel, well-known for hosting the international art-event Documenta, to see “Ich sehe was, was du nicht siehst”, an impressive exhibition of paintings, sculptures and installations by artists with ASD from Germany. More than 180 artists submitted their artworks to a jury, which included well-known artists, such as Konrad H. Giebeler, as well as the Hamburg-based art group “Die Schlumper” or Adolf Beutler, who received the 3rd place prize in the first EUWARD contest (European Award Painting and Graphic Art by Artists with Mental Disability 2000).

On June 5th, Mrs Heike Vogel gave a presentation on the Education of young autistic people through vocational training centres in Germany (more information on page 10) a discussion followed. The presentation echoed the draft report produced by Autism-Europe on Inclusion and employment of persons with ASD, in the framework of the European Year against Poverty and for Social Inclusion that will be made available on Autism-Europe’s website. Another session was devoted to the adoption of the Lisbon Treaty and its possible implications for people with disability.

During the meetings, chaired by the President Evelyne Friedel, Autism-Europe’s members were informed about the main activities of the association. In recent months, Autism-Europe has been advocating the rights of people with ASD, in particular towards the European Commission in the context of the drafting of both the Disability Strategy 2011-2020 and of the more general EU2020 Strategy. Autism-Europe has highlighted the particular needs and concerns of people with ASD and of people with complex needs. These two strategies will frame the policies of the European Union for the next decade and it is therefore of the utmost importance that the concerns of people with disability are properly considered.

Autism-Europe has launched its new website which has been designed to be more user friendly and to more effectively disseminate information about the organisation and about Autism.

On World Autism Awareness Day, Autism-Europe, with the cooperation of Autism Speaks, took part on a global bell ringing ceremony in the NYSE stock exchanges.

Elections were held during which several Council of Administration members were re-elected.

Autism-Europe is delighted to welcome new
members in the Council of Administration: Minnie Boey from the VVA (Belgium), Carole Povey from the National Autistic Society (UK), Fred Stekelenburg from the NVA (the Netherlands) as well as two self-advocates: Jan Verhaegh (the Netherlands) and Pietro from Italy. We look forward to cooperating with them in the future. We would also like to address our warm thanks to the retiring CA members for their valuable cooperation and support over the last years. Moreover, APLA, an association from the Czech Republic, has also been welcomed as a new full member.

Members of Council of Administration received an update on the preparation for the IXth International Congress in Catania. Further information are available in this issue, and on the website, in particular the programme of the Congress: http://www.autismeurope2010.org/.

Looking to the future, the venue of the Autism-Europe Congress 2013 has been agreed. The choice was difficult as Autism-Europe received impressive applications from three organisations: from APLA (Czech Republic), the Hungarian Autistic Society (HAS) and TODEV (Turkey). The proposal from HAS was accepted, and Autism-Europe’s Xth International Congress will therefore take place in Budapest in 2013.

The Council also elected the President for the forthcoming mandate (2012-2016). Zsuzsanna Szilvasy is the President of the Hungarian Autistic Society and has been a member of the executive committee since 2008. She has been very active reinforcing AE network in Eastern and Central Europe and building capacity of parents and self-advocates to help them better defend their rights. Zsuzsanna is the mother of two boys, one of which has autism, and during her HAS Presidency a national Strategy for Autism has been adopted by the Hungarian Government.

The main aspects of the Triennial strategy for the period 2011-2013 were presented to the council of administration. The Strategy, prepared by the Executive Committee has been submitted to the European Commission with a view to securing a subsidy, under the PROGRESS programme for equality and anti-discrimination 2011-2013, to support Autism-Europe’s running costs.

The emphasis is put on the reinforcement of Autism-Europe’s network capacity to advocate for the rights of persons with autism as well as on the engagement of Autism-Europe to represent them towards the EU institutions and cooperate with other EU networks to combat discrimination. Several major themes will be dealt with, in particular the UN Convention on the rights of persons with Disability and its implementation, de-institutionalization and community living, inclusion of persons with ASD (notably through access to education and employment), etc.

Finally we would like to thank very much Autismus Deutschland for welcoming us so warmly over the three days and for supporting Autism-Europe’s work and meetings in Kassel.
Autism-Europe and its members stand for Autism

Autism-Europe celebrated World Autism Awareness Day 2010 with the first-ever global bell ringing across NYSE Euronext markets in Europe and the United States in cooperation with Autism-Speaks. All over Europe, AE members also organized events, here is a non-exhaustive selection...

On December 18, 2007, the United Nations General Assembly adopted resolution 62/139, tabled by the State of Qatar, declaring April 2 as World Autism Awareness Day (WAAD) in perpetuity. This UN resolution established WAAD with the goal of bringing the world's attention to autism, a pervasive disorder that affects tens of millions.

World Autism Awareness Day shines a bright light on autism. WAAD activities help to increase and develop world knowledge about autism and impart information regarding the importance of early diagnosis and early intervention. Additionally, WAAD celebrates the unique talents and skills of people with autism, and features community events around the world where individuals with autism and their families are warmly welcomed and embraced.

In 2010, Autism-Europe with the cooperation of Autism Speaks and NYSE Euronext highlighted the third annual World Autism Awareness Day (WAAD), a day prior to WAAD, and Autism Awareness Month with the first-ever global bell ringing across NYSE Euronext markets in Europe and the United States.

NYSE Euronext locations in New York, Amsterdam, Brussels, Lisbon and Paris opened or closed the trading day with representatives from world autism organizations to raise awareness of autism, a disorder that affects millions of individuals and families around the world.
Armenia

In Armenia the Autism Awareness Day was celebrated by Autism Overcoming and Children First NGOs. In the premises provided by UNICEF, the NGOs organised an exhibition of works made by autistic kids attending the International Child Development Center - paintings, craft works etc. The exhibition was attended by other NGOs, specialists and general public.

Belgium

The Belgian association APEPA celebrated the WAAD with a performance of the play « Niets » of Nic Balthazar - featuring a 17-year-old autistic boy - and with the projection of the movie « BenX », adapted from the play. The day ended with a debate on autism awareness involving parents, professionals but also representatives of the federal and regional government.

Finland

In its Helsinki Central Office, the Finnish Association for Autism and Asperger’s Syndrome (F.A.A.A.S) celebrated WAAD by having an Open-doors-day together with the opening of the Art Exhibition “Autism Inside Out – the Journey to Autism Awareness” by Pia Hämäläinen, a person with high functioning autism.

United Kingdom

A group of 19 ‘autism organisations’ in the UK used three of the quality daily newspapers to promote awareness of autism under the banner ‘Stand up for Autism’. The advertisements were placed over the three days (one paper each day) leading up to 2nd April (Good Friday). Data shows that the number and range of ‘clicks’ on the WAAD website grew substantially during and shortly after the campaign.

In the North West of England, Autism Initiatives UK, together with three other autism charities, created a leaflet for regional distribution. The collaboration, and the leaflet, were considered a big success and the group is seeking to expand to include more ‘autism support organisations’ and to increase the scope of the awareness campaign for 2011 and beyond.

Greece

At the occasion of WAAD, the Greek Society for the Protection of Autistic People (GSPAP) organized events in Ioannina, Athens and Geraka Attikis, which attracted a wide audience and were reported by the media. The activities included addresses by Doctors, the President of GSPAP Professor Christos Alexiou, siblings and carers of autistic people as well as an exhibition of books and the showing of a film about Autism entitled “Elle s’appelle Sabine”.

Hungary

Hungary has successfully joined the “Light it up blue” campaign, on the World Autism Awareness Day. The most prominent building in Hungary, the House of Parliament, was lit up on the night of April 1. The event was extremely successful because of the large media’s interest. The building was beautiful and striking in blue color! In addition informative materials were distributed to the press. Due to the success, it is planned to repeat that kind of event over next years and to complete it with other happenings.
Italy
On April 2, the second season of CinemAutismo took place in Turin, an entire day organized by AMNC - with the support of ANGSA Piemonte Onlus and Gruppo Asperger Onlus - dedicated to projections of films on the subject, ideal departure for seven speakers - divided between afternoon and evening - to talk about autism from different perspectives: as a parent, as a brother or sister, as a psychologist and as autistic.

Slovakia
The Society for the Help of People with Autism Slovakia (SPOSA), has organized an information campaign called “Waterball Day 2010” on the occasion of WAAD. People had an opportunity to better understand autism by their self-experience. Waterball symbolizes the life situation of a person with ASD - living in the own world.

Spain
APNA
Following the call from the World Autism Organization – WAO – the Association of Parents of Persons with Autism – APNA – held an event promoted by FESPAU and the District of Hortaleza (Madrid, Spain). Physicians, paediatricians, teachers, representatives of government, families, filled the room and accompanied APNA on the eve of Easter holidays. We all learned a little bit more about People with Autism and their needs, their peculiar way of being and doing, and the state-of-art in research. Ballons were released at the end of the day in a joyful moment gathering many people from the civil society.

Autismo Burgos
At the occasion of the World Autism Awareness Day, Autismo Burgos published a tale titled “The silence of Camilo”, written by Maria Jesús Jabato and illustrated by Laura Esteban. Camilo is a boy with autism whose brother is just born. The tale was introduced in Burgos on 29 March, where artists played the tale to children from several schools of Burgos. The book is written in English, French and Spanish. Before the act, a press conference was given by representatives of Autismo Burgos and the authors of the book.

Roman Switzerland
Six associations from Roman Switzerland working for people with autism in partnership with the “Ecole Polytechnique Fédérale Lausanne » (EPFL), the University Hospital Centre in Vaud (CHUV) and the Swiss film library organised the premiere of the movie « Adam » from Max Mayer on the occasion of WAAD. 500 people gathered at the occasion.

Germany
Maria Kaminski and Bettina Bönsch, from Autismus Deutschland, travelled to Almaty, Kazakhstan, where they visited various institutions and provided assistance and advice for autistic persons and their families. During their stay they lived with families of autistic persons. Mrs Kaminski encouraged them to hold a congress on autism in Central Asia as well as to create an organization to advocate for autism in Kazakhstan. She met with the education secretary and gave an interview for a German Radio station and a press conference. A conference was also organized in Germany (Köln).
The programme of the IX International Congress of Autism-Europe in Catania is now available online:

www.autismeurope2010.org

The Congress covers all the recent scientific, political and social advances in the field of Autism Spectrum Disorders. The radical innovation that has taken place in the last years makes this Congress too important to be missed.

State-of-the-art lectures:
- Sir Michael Rutter, Honorary Director of the Medical Research Council Child Psychiatry Unit: Progress in understanding autism: 2007-2010
- Giacomo Rizzolatti, Full Professor, Director of the Department of Neurosciences, University of Parma - The mirror neurons and ASD
- Catherine Lord, Director, Autism and Communication Disorders Center (UMACCD), University of Michigan, USA - Towards DSM V- new trends in diagnosis and classification of ASD.

List of Symposia:
- Health policies for ASD
- Early diagnosis and intervention in ASD
- Social development and cognition in ASD
- The neurobiology of ASD
- Environmental risk factors for ASD
- Psychological functioning in ASD
- Brain anatomy in ASD
- Genetics in ASD
- Promoting the rights-based approach to ASD
- Mental health issues in ASD
- Meeting the special needs of persons with ASD
- Understanding and meeting the evolving needs of persons with ASD across the lifespan
- Employment for persons with ASD
- Medical treatments in ASD
- Autism in girls and women
- Supporting and including adults with ASD
- Internet and assistive technologies
- Building for Autism

Round Table: The science and fiction of autism

Poster sessions:
- Genetic and biological features in ASD
- Supporting social understanding and inclusion of adults with Asperger Syndrome
- Treatment, education and services for ASD
- Diagnosis and assessment
- Communication development and early intervention in ASD
- Genetic and biological features in ASD

Parallel events:

Workshop:
Treatment of Severe Behavior Problems and Feeding Disorders in Individuals with Autism: Advances in Applied Behavior Analysis

Conference:
The Ace Project Conference: Including persons with Asperger Syndrome in society

At the occasion of the IX International Congress, Autism-Europe is honoured to welcome the world most renowned experts in the field of Autism. For further information about the speakers, the content of the symposia and poster sessions, as well as for registration, please visit Autism-Europe’s IX International Congress website: www.autismeurope2010.org.
Prizes of “touches of autism” - V international art exhibition of people with autism.

On 8th June 2010, the Jury met at Autismo Burgos to choose the winners of the V International Art Exhibition of People with Autism. The jury was composed by:

- Mr. Ignacio Gonzalez - Representative of the City Council
- Mrs. Maria Jesús Jabato - Writer
- Mrs. Laura Esteban and Mrs. Carmen Palenzuela - Artists
- Mr. Javier Guadilla - Member of the Council of Administration of Autismo Burgos

The awards will be given at Catania’s Congress.

The Jury considered the composition, the quality and also valued that artworks apply the main characteristics of the artistic expression in people with autism. Each edition attracts more artists interested in this initiative. This time, up to 158 artists have participated, belonging to 40 organizations and 15 countries (Panama, Mexico, Italy, Luxemburg, Belgium, Argentina, Colombia, Lebanon, France, The Czech Republic, Portugal, Greece, Great Britain and Spain).

Catania’s opening and following venues this year

The Exhibition will be opened in Catania, during the IX International Congress of Autism Europe (8th -10th October 2010). Then it will be shown in the AETAPI Congress (main Spanish Association of Professionals in the field of Autism) in Zaragoza (Spain) in November 2010.

In December, the Regional Administration Junta de Castilla y León will show the Exhibition at the Regional Parliament, in Valladolid, during the International Day of People with Disability.

Autism-Europe launched its new website

www.autismeurope.org

Autism-Europe has launched its new website with a new design to make it more “user-friendly” and ease the navigation. You can now find easily information about AE’s campaigns and fields of activities.

From now on, Autism-Europe’s electronic newsletters will also be sent through the website, so you can subscribe to the Newsletter online. It is very easy!

Do not hesitate to visit www.autismeurope.org! Autism-Europe would like to enrich the linguistic variety of the website. Please send us any translation of AE document that you may have in your national language or any document of interest for the other members. We will be happy to publish them! Many thanks for your cooperation.
Employment and inclusion of persons with ASD

The Abensberg Vocational Training Programme (ATP) and Job Placement of People with ASD in Germany

After having finished school, young people with ASD together with their parents usually ask themselves: “Where do we go from here? Where will we live and earn our living? What perspectives do we have in the first place, and what possibilities of vocational participation are being offered?”

Vocational training and inclusion of adults with autism spectrum disorders constitute a key challenge to the working world in the new decade.

International studies show that only a small number of people with autism spectrum disorders have a job. 2/3 – 3/4 of all adults with autism seem to be excluded from any working process whatsoever. 15 follow-up US and UK studies compiled by HOWLIN revealed that since 1980 only an average of 24% have a job, whereby a large number of them are working in a sheltered workshop (cf. HOWLIN 2003).

Several studies made in the USA, in Great Britain, in Germany and in Australia came to the same conclusion: Only 2-6 % of the people with ASD have a full time job on the regular labour market.

What all the more pitiable is that most of those who have a regular job have to accept an employment that is significantly below their potentials and educational level.

Job situation in Germany

The Federal Republic of Germany has established a nationwide system of workshops for disabled people. This is where the majority of adults with autism (ca. 65 %) usually work. Those who are not able to find employment on the regular labour market, have the right to work in sheltered workshops.

Today, however, young people with ASD in Germany are diagnosed earlier and trained more specifically in various kinds of schools and thus get higher school degrees. Thus, the discrepancy between individual potentials and real vocational prospects has increasingly grown. But instead of 5% today 15 -20% of the young people might have found a job on the regular labour market.

Nonetheless, about 30% are not included in the working process.
Among them are severely and multiply disabled people with autism as well as young people with good and above average school degrees. Vocational training or jobs were not available and thus - considering their skills - they seemed to be totally misplaced in the workshops.

The discontent of these people and their families led to the German Federal Ministry of Labour and Social Affairs commissioning a Vocational Rehabilitation Centre (Abensberg) to help include them in the regular labour market.

Two research projects must be mentioned in this context that particularly dealt with what services and general conditions are necessary for people with autism to participate in the working, and what job opportunities are being offered.

51 vocational training centres (external facilities for vocational rehabilitation) have been established in Germany, each of them for about 300 young people with all kinds of disabilities. Here the adolescents undergo specific job-related tests. They are offered pre-vocational training but also training courses for 50 different jobs. The generally recognised courses have been reduced as to theory, but as to practical matters they meet the general requirements.

The aim of the facilities is to train young people with disabilities in generally recognised jobs and then to place them on the regular labour market.

The Abensberg Vocational Training Programme (ATP)

In the last 7 years we have established a network for vocational training in order to offer vocational training to the largest possible number of adolescents with ASD. The personnel of 4 specific training centres were systematically prepared to assess young people in individual tests and offer vocational training. Today there are 12 centres that offer this kind of service to the young people.

The number of externally trained people with autism has increased in a few years to now about 350. The growing number of participants with ASD in all training centres proves that there is a high demand for vocational training and future perspectives.

Qualifications and employment rate

Up to now (2010) 88 adolescents from 5 training centres have finished their training (3 – 3.5 years) successfully. All the others are still undergoing qualification- and training measures.

An evaluation study revealed that 46 graduates could be placed on the regular labour market, 14 found a job in one of the workshops for disabled people, 9 are undergoing further training measures and 19 are still looking for a job or cannot be placed on the regular market for various reasons.

Vocational training is as heterogeneous as the group of people itself, thus the young people were trained in jobs such as: office clerk, building industry worker, metal worker, gardener and horticulturist, electronic technician, painter, varnisher, carpenter, warehouseman, IT-specialist, IT-system technician, textile cleaner, information technology officer, retail dealer, tailor, motorbike and bicycle mechanic, assistant cook, butcher and baker.

There is no doubt about people with ASD, especially those with Asperger’s Syndrome, being able to finish successfully vocational training and find a job on the regular labour market.

A completed vocational training is the prerequisite for getting a self-chosen and productive employment, which is what enables the young people to live a life as independent as possible with the least of restrictions in the first place.

However, vocational success requires the following framework conditions that have been integrated in the Abensberg ‘Vocational Training Programme’ (ATP):

What is really important here is to identify the skills and dispositions of the young people with the help of a differentiated assessment, and then to find an adequate field of activity. People with
autism are dependant on working conditions that take account of their special needs. They are dependant on teaching strategies that take account of their learning habits.

They need – at the beginning – a specific work environment and individual support at the workplace. Modified examination conditions have to compensate possible disadvantages.

What is important too is to create adequate framework conditions for a future that includes social and vocational inclusion. Thus, training measures to develop skills needed in everyday life, adequate forms of residence, social skills training to better understand the sublime rules at work and in everyday life as well as help in organising leisure time are absolutely necessary. After having finished the training integration services for people with disabilities support the young people in finding an adequate job.

We are convinced that adolescents with autism spectrum disorders are able to participate in one way or the other in the world of work.

People with autism have the same right to participate in the working life like everybody else. They have the right to find a job according to their interests and be offered support. We are very optimistic that in the coming years not only the number of young people with ASD having qualified job will be increasing but also their happiness. It is up to us to create the conditions to make this possible.

(Literature can be directly obtained from the author).

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The LEM cooperative in Milan

In 2007 some individuals with Asperger’s syndrome from Milan decided to make their dream come true by creating a working reality adapted to them. The frustration they went through each time they had to face complex and hostile working conditions plus the dissatisfaction with their professional situation drove them to find their own way of making the most of their special skills.

They shared common experiences of loneliness, incomprehension and disappointed aspirations. Founding a cooperative with independent management seemed to be the best way to share a life project with other people like them.

The LEM (Laboratoria di Esplorazione Multimedinae/Multimedia Research Laboratory) cooperative was founded to build on the special skills of its employees in various activity fields, such as graphics, informatics and linguistics.

In addition to graphic works and website designs (such as www.asperger.it, www.fantasiaautismo.org, www.culturautismo.it, etc.), the LEM has translated books for the publisher Erickson.

In 2008, thanks to its knowledge and experiences, it drafted the booklet «Who is afraid of the spectrum?» (http://lem.coop/chihapaura.html - in Italian) intended to provide a first but significant approach of the Asperger’s syndrome.

In 2009, the LEM took the ambitious step to become a publisher under the name of LEM LIBRARIA. It translated and published the «Guide of survival for persons with Asperger’s syndrome», drafted by Marc Segard for «boys like him». Marc Segard died in 2003 in a car accident.

In May this year, the LEM produced the Italian edition of the book entitled «Asperger’s Syndrome and sexuality», drafted by the Canadian psychologist Isabelle Hénault. Other books are currently in preparation.

Since several months, in view of creating employment for young people, the cooperative, in collaboration with the city of Milan, has developed and managed a training course on digitization of documentary archives currently attended by 7 young people.

Besides its production activities the cooperative encourages and manages various non profit-making initiatives complying with its statutes, for example: the Nautilus Complex, a place for young people with Asperger’s syndrome to meet and promote cultural events.

Fabrizia Bugini (President)
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Latest activities

Since the beginning of the project, all participants with ASD have created a Facebook account and have started communicating online, under the supervision and with the support of the project partners. A battery of test has also been created by Dr Johnny Lawson from the Oxford Bridge University in order to measure the benefits of the project for the participants.

The partners project (Autism-Europe, Estonian Autism Society, Oxford Brookes University and Autism Romania) travelled to Ljubljana with their delegations and were welcomed by the lead partner of the project: Centre for Autism Slovenia.

It gave delegates with ASD the opportunity to meet for the first time in real life their counterparts from other countries that they had, for some of them, already met online. During their stay in Ljubljana they were able to get to know each other through various social activities. Various workshops and visits allowed them to learn more about Slovenia and its capital. They also had the opportunity to meet with the President of Autism-Europe for a questions and answers session.

A press conference was organized in order to raise awareness of Autism in Slovenia and inform about the project objectives. On the last day, a high level conference “inclusion: switch from minus to plus” gathered the project participants as well as various representatives from Slovenian DPOs and ministries to discuss the issue of rights and inclusion of persons with disability and in particular of persons with ASD. Several speakers from various EU countries: France, Hungary, Czech Republic, UK, etc, shared their expertise and good practices with the audience.

Forthcoming Activities

In October, participants are invited to take part in the IX Autism-Europe International Congress in Catania, where a parallel conference will be organised about the project, with the cooperation of international experts in the field of Autism. They will have the opportunity to network with delegates from the entire world and discover Catania and Sicily. In the meantime, they are encouraged to keep in touch and socialize via Facebook.
Participation of Autistic People in Europe - PAPE

1. Introduction

PAPE – Participation of Autistic People in Europe develops a Current Attainment Tool (CAT) to assist people with autism to complete a Europass. The Europass is a web based curriculum vitae freely available through the EU. After the conclusion of the project in February 2011, the CAT will be available for all adults with early childhood autism. It documents the skills and competencies from the user's perspective and has several advantages:

1. It focuses on the user's skills and formulates goals.
2. The description is exclusively positive, strengthening the user's self-esteem.
3. If the person changes into a new institution or there is staff turnover, the CAT is used as an instrument to facilitate these changes. Through its positive form, it draws attention to the abilities of people with autism and strengthens the motivation to offer more activities.
4. The families of the persons affected can also contribute with their knowledge and improve the overall situation of their affected relatives.
5. Through the concrete description of their skills, the CAT supports a new perception of people with autism in society.
6. Independently of specific methods of working, the CAT can be filled in/used centered on the client.

The practical experience of working with autistic people consistently confirms the paradigms and descriptions of the scientific literature. Through the collaboration of different institutions with their different perspectives but similar attitudes towards the support of people with autism, the attention is turned on the user's perspective. The underlying philosophy of the CAT is the appreciation of the individuals and the assumption that lifelong learning and the development of abilities is possible.

Especially while working with autistic people, particularly with the part of the spectrum with early childhood autism, it is often noticed that guidelines which are made for people with disabilities are not adequate for this specific group of people. That is why in many areas (for example vocational training, adult education, social training, and integration), new and more adequate methods are in demand. Looking across borders inspires with new ideas and points of view because every country has different political systems, attitudes and, accordingly, approaches.

For the involved partners, the previous success of the project PAPE is already impressive. At the same time, through intensive exchange of information across national and linguistic borders, a profound discussion about attitude and philosophy in working with autistic people takes place, which benefits the affected persons on different levels.

The CAT assembles modules that are presently tested on their practicability in all partner institutions. The autistic persons are involved in this first testing phase.

During a concluding conference in January 2011 in Germany, the final version of the CAT and the results of the evaluation will be presented to the specialised public.

The consortium presents itself with own presentations on the website www.project-pape.eu. All results from the project PAPE are available there. The instrument is translated in all the languages of the partners: English, German, Portuguese and Czech.

2. Project Objectives

The goal of the project is a record of current attainments which contributes to completing the Europass. The Current Attainment Tool (CAT)*, (in German "Zertifikat meiner Kompetenzen (ZmK)") is especially tailored to people with early childhood autism. It allows the documentation of the user's own abilities and skills. The following content is included in modules:
- Formal Curricula,
- Non-formal Curricula (Mobility, use of public institutions),
- Professional core competencies (use of the computer, behaviour at work, etc.),
- Social competencies (communication, affect control, etc.),
- Show personal development (reflection on the condition, planning competence, i. a.).

The CAT is designed to reflect the CAT user’s (self-) perception. That is why all the given answers (and answer boxes to tick) are formulated in the first person. As much importance as the actual documentation is attached to the process of working on the CAT, either with or for the user (in case he/she does not have the ability to communicate verbally or in written form).

Through its computer-based format, the Current Attainment Tool enables dynamic entries, which can continuously show the development in the person’s life. The instrument is autism-/ASD-specific and centered on the person. It can be revised over and over because – in accordance with the joint conviction and experience of the involved partners – a person’s development is never completed. The instrument always shows the current state the way it is perceived by the user or assumed. Changes are documented in a self-reflexive way. People with autism are rarely asked to give their own assessment, which is why the CAT has particular value for them. It is also important to acknowledge and, if possible, change this in society as a whole.

The purpose of the CAT is to foster transparency and recognition of the abilities and competencies of people with autism. For this, not only curricula are tested, but above all, competencies of day-to-day life, which often already present a big challenge for people with autism, are documented. Autistic people have to work hard to acquire competencies that for other people are self-evident. These competencies are named in the CAT and documented as abilities, including the progress made.

That is why these activities are also described in small steps in the CAT. This subtly differentiated view has the purpose to enable people with autism (as well as staff and family) to consider developing the abilities further.

In contrast to documents that emphasise deficiencies, the CAT also explicitly highlights the possibility for personal development for the concerned persons and, thereby, makes it more accessible. This increases the motivation to pursue one’s own development, entailing a better social integration.

For family and staff, the emphasis on competences can direct the focus of attention away from disabilities and towards abilities and, through a changed perspective, provides the opportunity to broaden the range of activities offered to people with autism.

Another important goal of the CAT is the structured exchange across institutions and borders. Up to now, documentation systems are mostly disability oriented. Positive abilities that the person does not display clearly or only infrequently are often only known to a small part of the staff. If there is staff turnover or the person moves to a different institution, this knowledge is often lost. The development of the concerned person cannot be built on this knowledge.

This is also an important reason why changes are often traumatic for concerned persons and go hand in hand with long periods of adjustment. Here the CAT can offer a ground-breaking way of assistance.

3. Project Approach

The consortium unanimously found that the one and only method or approach towards working with autistic persons does not exist! Besides training the staff, it is, above all, crucial to focus on the persons with autism and on their abilities and interests in order to support them positively. The different political situations and the varying value attached to socio-pedagogical work with disabled people play an important role, which is reflected in the staff ratio and qualifications as well as in adequate facilities.

Through intensive discussions in 4 (Germany, Portugal and Ireland) international meetings that enabled to exchange, explain, discuss and reflect on attitude and approach towards people with autism, it became possible that all five partners contribute in equal parts to this complex instrument. Here it is an advantage that the members of the consortium not only share, but at the same time have many different experiences in their work. Some of them are themselves parents of adults with autism and, thus, have extensive and detailed practical knowledge. Furthermore, all members of the consortium are in leadership positions and, thus, have significant influence on content and direction of their institution’s work.
The consortium has agreed on designing the instrument broadly so that every institution, across countries, can work with it using its own methods and can achieve the desired effects like motivating further education and training and increasing the self-esteem of the person with autism spectrum disorders – independently of fixed methods! The underlying philosophy of the Current Attainment Tool is appreciation: That is why all statements on abilities and competencies are formulated positively.

4. Different Areas of Life and Competence

In the first year of the project, the Current Attainment Tool including the modules has been developed to the point that it can be tested now, in a first phase, on its usefulness and handling in all five partner countries. For this, the different areas of life and competencies (see chart 1) that can be put into statements, are listed as declarative sentences in a computer-based format.

With the help of a computer, the users themselves or an assistant can tick the given statements, amend them or skip them. Afterwards, the personal statements are compiled according to subject areas, printed and, thus, made available in hard copy form.

With its multitude of topics and areas, the CAT is designed to show as many areas of the user’s life as possible. As it is, at last, impossible to list all areas, the CAT allows the user to add individually important subject areas as needed. The purpose of the testing phases is to show if the offered subject areas sufficiently cover the spectrum of potentials and whether important areas are missing, which will be added afterwards where necessary. In the existing form, at the end of the document, there is the possibility to point out what is missing or difficult in the CAT.

On this basis, a possible revision has been discussed at the last meeting in March 2010 in Lisbon. The revised draft will be tested in a second phase by the partners of the consortium as well as by new institutions in the partner countries. The Lead partner in Germany will exemplarily evaluate the results of the overall process and of the effects envisaged and attained by the use of the CAT. In the second testing phase, partner institutions that were not involved in the development of the instrument will participate in order to check if the instrument displays everywhere the expected benefits and is easy to manage. After the testing phase, the results received until then will be published on the website.

By the time of the concluding conference, two publications will be released in the specialized press in every of the five participating countries. These publications in their respective national languages contribute to the involvement of new partners as well as to further dissemination. The concluding conference will take place with one representative for every partner institution in Giessen/Germany.

The presentation of the CAT as well as the presentation of the evaluation’s findings will be the main points of the agenda. Furthermore, a workshop will introduce the use of the CAT. The target audience is experts as well as policy-makers.

Isabel Cottinelli Telmo,
APPDA-Lisboa, Portuguese partner of PAPE

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APLA – New full member from Czech republic

APLA (Association for persons with autism) was founded in 2000 by parents of children with ASD and professionals in the field. APLA is a non-profit organization which aims at providing or supporting quality services to children and adults with ASD. APLA was also established with the objective of advancing advocacy and awareness. The main mission of APLA is to enable individuals with ASD to reach their highest potential and contribute as confident and satisfied individuals to their community.

APLA is a nationally recognized leader in the knowledge of ASD. It serves as a model or a source of information for others who develop services and programmes for people with ASD. The APLA staff is largely involved in increasing awareness of the specialist and general public in this field. APLA participated in the production of a number of educational programmes in public service broadcasting (Czech Television, Czech Radio Broadcasting), in publication activities and education of both specialists and parents. APLA presents lectures in secondary schools and universities.

APLA is a guarantee of serious information, programmes and approaches. The APLA key staff are among renowned specialists in autism in the Czech Republic, they participate regularly in international conferences and educational events and gather experiences from foreign information sources and various types of educational events. APLA also takes part in meeting the quality standards of social services in the Czech Republic.

APLA is a well functioning organization with a stable background and very good cooperation between parents and professionals. A lot of staff including board have their own children with autism. Across all programs, APLA has served thousands of families affected by ASD. APLA’s work is based on several methodological pillars, shortly it is an eclectic mainstream approach coming out from various but not all theoretical sources and general attitudes. Programs are mainly rooted in principles of:

- Techniques of structured and visualised teaching
- Person centered and highly individualized approach
- Support of both mainstream and special education
- Alternative and augmentative communication
- Cognitive and applied behaviour analysis
- Scientific approach
- Social and law support of families

APLA has experience in preparing and implementing demanding projects, including projects funded from the
European Social Fund focused on human resource development, supported employment, therapeutic services and education. Other implemented projects supported by the European Union concentrate on training of the educational staff, support of parents and introduction of specific educational methods in schools where students with ASD are integrated.

Activities and services of APLA

- Diagnostic and Functional Assessment
- Family Early Intervention Home-based Program
- Work Skills and Job Training Program
- Social and Communication Skills Training Program
- Respite Care, Special Freetime Activities
- Political and Social welfare lobbyism
- Solutions of challenged behavior prevention (therapy, crises scenarios, self defence)
- Educational Interventions and consultancy
- Promotion of better understanding and awareness of ASD. Training of professionals and rising public awareness (internet, Facebook, t-shirts, information leaflets, educational brochures and books, annual reports, newsletters, conferences).
- APLA currently operates one community living residence for 6 people with high support needs arising out of severe challenging behaviours, who were unable to live in any other community or institution.
- Education and empowerment of families affected with ASD and their advocating.

In June 2010 in Kassel, APLA was accepted as full member of Autism-Europe, we are very thankful for this opportunity and we are looking forward to future cooperation and experiences.

We hope, that in 2013 APLA will be succesful with the proposal for the Autism Europe Congress 2016. This world important event would bring to our country huge amount of educational support, public and professional awareness. By organizing the conference we would be happy to devote another piece to APLA’s motto:

„We help the world to understand autism and people with autism to understand the world.“
Plans for a European Public Health Policy on Autism

As Europeans we sometimes revel in celebrating the uniqueness of our own countries and the differences between “us and them”. Europe has many different languages, cultures and models of government but there are certain causes that can truly bring us together. During March of this year a group of professionals and parents from across Europe gathered in Luxembourg as part of a European Commission funded Panel of Experts Meeting to discuss the challenges and opportunities across Europe in terms of autism.

The European Commission’s DG SANCO oversees health for citizens of European member states. The Luxembourg Panel of Expert Meeting on Autism funded by DG-SANCO was tasked with discussing public health and autism, and invited to come up with initial recommendations about the strategic way forward. Over two days, representatives from 14 European countries discussed some of the issues that they were facing in their own countries concerning autism. Presentations were made by various international experts, including Dr Michel Favre from Autism Europe who outlined the excellent work this organisation does in terms of advocacy and information sharing.

Those at the Luxembourg meeting realised that there must be at least three dimensions to any public health policy addressing autism in the EU. These are a policy dimension, a responsibility dimension, and a national dimension. The first dimension requires a focus on knowing:

- what are the causes of autism (research of risk factors);
- how to raise public and professional awareness;
- how many individuals in a population have autism (prevalence);
- what are the best treatments or services;
- what recommendations and guidelines should be in place for future planning.

For each strand from the policy dimension, consideration needs to be given to the second dimension, which is where the primary responsibility lies. Five potential leaders were identified:

- people with ASD;
- their families and carers;
- health, education and policy professionals;
- national governments;
- the EU itself.

The third dimension is to consider the diversity of the 27 EU member states. Indeed, each country differs in their approaches to ASD and in the policies and services they have for individuals on the autism spectrum.

A document summarizing the meeting and the panel’s recommendations can be found on this website http://www.autism2010.eu/consultation_process.htm: there is an ongoing consultation phase, so comments and advice can be left for the authors as they prepare future drafts.

The next step is to hold a further consultation phase in Budapest and Majorca in September. These meetings are supported by an EC Executive Agency for Health and Consumers grant awarded to Irish Autism Action and the European Autism Public Health Alliance. They are being organized in collaboration with Autism Europe and Autism Speaks and represent a joint effort to provide as broad a community consultation as possible. The output of these meetings will be a strategic document written by the authors of this article designed to set out coherent recommendations for a public health policy across the EU on ASD. The document will be finally published and presented to ministers at an event in Dublin in November.

This is an exciting time for autism in Europe. More is being understood from research. We are developing good models in terms of service delivery. Awareness is slowly rising - and some countries have been successful in terms of legislation. However, there is still a way to go. The Luxembourg meeting showed how the European community can work together to speak with a single voice on autism. It is hoped that before the end of the year a policy document on autism and public health will be written to provide recommendations for policy makers and ultimately better outcomes for families.

Sir Christopher Ball,
Dr Alvaro Ramirez,
Dr Simon Wallace*

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The Innovative Medicine Initiative is planning to launch a Call for proposals in Autism

The Innovative Medicines Initiative (IMI) is a public-private partnership between the European Union, represented by the European Commission, and the pharmaceutical industry, represented by the European Federation of Pharmaceutical Industries and Associations (EFPIA).

The European Union and the pharmaceutical industry have joined forces to make the drug discovery and development process in Europe more efficient and to enhance Europe’s competitiveness in the pharmaceutical sector.

The improvements to the drug development process will benefit patients and society, by generating faster access to better medicines. Research focuses on finding better methods for predicting the safety and efficacy of new medicines in disease areas that affect millions of Europeans, such as brain disorders as Autism, inflammatory, metabolic and infectious diseases, and cancer, while some projects aim specifically to improve knowledge management or education and training in biopharmaceutical research.

IMI’s total budget amounts to € 2 billion. € 1 billion is invested from the European Commission’s Seventh Framework Programme (FP7), which is matched by contributions from EFPIA and its member companies.

The European Union’s contribution (public money) funds exclusively public organisations or non-profit organisations and small and medium-sized enterprises (SMEs). Pharmaceutical companies fully fund their own participation and provide R&D resources such as staff, laboratories, materials and clinical research.

Funding is distributed through open calls for proposals following an independent peer reviewed twostage process (further information on http://imi.europa.eu/calls_en.html)

As output of its 1st Call for Propositions 2008, IMI is currently funding 15 Full Projects totalling an investment of € 246 millions.

In the 2nd IMI Call proposals 2009, 9 Topics have been launched with a total budget of around € 156 millions. The 2nd Call is currently at its 2nd Stage of evaluation and it is expected to generate 9 new Full projects by the end of 2010.

IMI is planning to launch a Call Topic on Autism in its 3rd Call to be published in the last quarter of 2010.

The indicative Call Topic is: Translational endpoints in autism

The project aims to take advantage of recent progress in the understanding of the underlying neurobiology of Autism Spectrum Disorders (ASD), and to foster the development and validation of in vitro models, in vivo models and translational biomarkers enabling drug discovery. Another key objective of the project is to establish a network of clinical centres of excellence across Europe that serves as an interactive platform for ASD specialists and clinical trials.

All information above is indicative and subject to change. Further details about the IMI 3rd Call topics will be communicated after approval by the IMI Governing Board.

All IMI projects prior to approval are thoroughly evaluated by an Ethical Panel composed by at least 5 Independent Ethical Experts, to ensure that all ethical issues (such as for drug therapy, clinical research and use of human participants and human material and information, data protection, and use of experimental animals) are properly dealt with.

There are no conflict of interest between IMI activities and Patients advocacy groups. Indeed Patients advocacy groups are important stakeholders of IMI and are represented in the IMI Scientific Committee (see http://imi.europa.eu/scientific-committee_en.html).

Patients organizations are welcome as participants to IMI consortia.

For further information please visit: www.imi.europa.eu
Questions by email: Infodesk [AT] imi.europa.eu
IX International Congress

AUTISM-EUROPE
A FUTURE FOR AUTISM

Catania, Italy
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