



European Autism Information System

EAIS NEWSLETTER

Issue 2

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Kathy Sinnott, MEP,
The Hope Project, Ireland

Welcome to the second of a series of newsletters developed as part of the European Autism Information System (EAIS) project. The newsletter will be sent out to Associated Partners, Collaborating Partners and any other interested parties and can also be found on the project website www.eais.eu.

The contents of the newsletter includes sections on the progress of the project, information on meetings, notable events and contributions from partners, which are most welcome. Please contact us at eais@hopeproject.ie if you would like to contribute or for general enquiries.



1st Welsh Conference on Autism Research:



Autism Cymru, which is Wales' national charity for autism, has joined forces with specialist autism research charity Autism Speaks to host the Inaugural conference on research that is dedicated to Autism.

The conference, which is to be held on November 9th in the National Museum of Wales, Cardiff, features an array of respected and outstanding speakers from the research world including:

Professor Martin Raff, University College London. Professor Anthony Monaco, Trust Centre for Human Genetics, Oxford and Dr Dawn Wimpory, University of Wales. Dr Alvaro Ramirez, The Hope Project, Ireland. Professor Mark Johnson, Birkbeck College London and Professor Declan Murphy, Institute of Psychiatry, London. Professor Anthony Bailey, University of Oxford, Lois Grayson, University of Cardiff and Professor Simon Baron-Cohen, Autism Research Centre Cambridge. Professor Martin Knapp, Institute of Psychiatry, London Dame Stephanie Shirley, Chair of Trustees, Autism Speaks will talk about the way forward.

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Anyone interested in attending this can find an application form at <http://www.autism-in-scotland.org.uk/news/documents/ResearchConferenceNov07.pdf>
More information can be obtained from Autism Cymru's website or call them direct on 029 2046 3263. Bookings can also be taken directly with Autism Speaks by calling Lynn Hart 01491 411569.



Second Panel of Experts on Autism, Luxembourg, 24-25 September 2007:

The 'Second Panel of Experts on Autism' meeting was hosted by DG-SANCO in Luxembourg on 24-25 September. This was a technical meeting attended by Associated and Collaborating Partners of the EAIS project and other interested parties. In total there were 23 participants representing eleven European Countries. The meeting was opened by **Kathy Sinnott MEP**, chairperson of the **Hope Project** and we would like to thank **Antoni Montserrat** who gave us a warm welcome to **DG-SANCO** and for his participation in the meeting.

The main thrust of the meeting was to agree the way forward for pilot studies to be implemented for estimation of ASD prevalence and financial burden in Europe as well as working towards a harmonised data collection system. Strategies for dealing with these issues were discussed at length and progress was reported by Work Package leaders.

Antoni Montserrat (Acting Head of Health Information Unit, European Commission DG-SANCO) gave a presentation of activities related to ASD in the European Commission. He highlighted the level of importance that has been given to ASD in terms of inclusion in the Health Strategy and the possibility of a Commission Communication on a European Action on ASD in 2009 / 2010. The importance of an EU Presidency nominating ASD as a health priority was emphasised by Mr Montserrat as a very effective way to strengthen the case for this action and it was mentioned that the EAIS project partners have already approached the Czech Republic Commissioner, Dr Spidla, in this connection. The importance of free circulation of patients in member states and a coordinated EU effort on rare diseases, including some ASD pathologies, was also discussed.

At the end of the meeting it was agreed that partners from Malta, France, Portugal, Spain, Italy, Luxembourg, Ireland and Czech Republic would try out the data collection system designed by **Poul Thorsen** and his team from NANEA, Denmark, with a limited number of patients. **Manuel Posada** (Fundación Carlos III, Spain) will have the "European Protocol for Autism Spectrum Disorder Prevalence" (EPAP) reviewed by external experts and made available on the website in the near future. **Renee Romeo** (Institute of Psychiatry, King's College London) agreed to distribute a scoping questionnaire related to the Financial Burden of ASD. This has already been sent to Collaborating Partners and is available on the website

http://www.eais.eu/downloads/EAIS_scoping_questionnaire081007_kcl.doc

It is hoped that all partners will follow up on the effort to identify pilot areas, as was discussed at length over the two day meeting. If any other organisation is interested in participating as a pilot area, we would be very glad to hear from them. Please contact us by e-mail at eais@hopeproject.ie for more information. The minutes of the meeting, as well as reports and presentations, are available on the EAIS website www.eais.eu



Launch of the European Autism Alliance:

The Launch of the European Autism Alliance (EAA) was held on the morning of the 17th of October in the Altiero Spinelli Building in the European Parliament, Brussels.

Speakers at this event included Kathy Sinnott MEP who started off the event with a welcome address and introduced Maria Carlshamre MEP (ACDE) from Sweden and Den Dover MEP (EPP) from the United Kingdom who both have great interests in Autism. Dr Alvaro Ramirez, the EAIS project Leader, and from the Hope Project, Ireland gave a project update and presented the EAA vision document. Antoni Montserrat, the acting Head of Health Information Unit, European Commission DG-SANCO, gave an update on the activities of DG SANCO related to autism. Dr Diana Schendel, Lead Health Scientist, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (CDC), Atlanta talked about the experience of the CDC in Monitoring Autism Spectrum disorders in the USA. Dr Jenny Longmore, Director of Research and Programmes, Europe Autism Speaks Inc presented information on autism research – moving the science forward.

A slide show of the photographic collection by photographer Lidia Costantini was presented. The presentation entitled “this is me!” was accompanied by the Depeche Mode song “Enjoy the silence”. This was developed by ULSS20, Verona as part of their work package in conjunction with Lidia Costantini. An article with these pictures appeared in Italian Vanity Fair to highlight ASD.

The launch of the EAA was to explain to people what the Association is going to be about; the EAA is to be created as part of the EAIS project, it will be a sustainable association committed to providing information on the main aspects of work currently being undertaken by the EAIS project, which are:

- early detection and diagnosis of autism for professionals
- management of data systems (surveillance)
- prevalence and financial burden of autism spectrum disorders in the EU
- issues surrounding public awareness of ASD.

The role of the EAA will include:

- Training (including an on-line distance learning platform)
- Distribution of software and information systems
- Providing a forum for health information professionals and managers, policy makers, ministries of health, academic and research organisations.

In this way the EAA will continue the work of the EAIS project by offering services to government and non-governmental institutions of Europe reflecting the findings and recommendations of the EAIS project. It will be unique in promoting epidemiological activities between policy makers, health services and institutions in the field of ASD in Europe.

The EAA will also be run as a non-profit organisation, financed by membership fees, income-generating services (such as training activities) and grants.

A list of key institutions concerned with autism data collection in Europe, including EU member and applicant states will be contacted as potential members of the EAA. The feasibility of the EAA will depend on funding, which will be sought in the form of grants in the first instance, with membership fees and revenue generating activities playing a role once the EAA has been established.

To make the vision a reality we need the collaboration and commitment of member states and the European Commission.



The EAIS brochure:

The EAIS brochure (below) was designed and printed by the ULSS20 Verona team, and was distributed at the launch of the European Autism Alliance in Brussels on 17th October. The EAIS logo has been designed around the idea of the 'Rubik's Cube', indicating the complexity of the condition. Please contact eais@hopeproject.ie if you would like to request copies .



Sunfield: Commitment to evidence-based practice

*Iain Chatwin,
Staff Development Co-ordinator*

Sunfield is a registered charity providing education and residential care for children and young people with severe and complex learning needs. The activity of the organisation is enhanced through the incorporation of an Assessment and Outreach Service (SAOS), a Professional Development Centre (PDC) and the Sunfield Research Institute.

Working with children and young people with complex needs arising from intellectual disability in co-morbidity with conditions such as autism spectrum disorders (ASD) requires that a sophisticated toolkit of responses is available to practitioners. Many strategies used at Sunfield are well established, such as TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children). However, there are different challenges to be faced each day as new and individual needs are identified. In order to maintain our ability to deliver appropriate education and care, a range of training courses have been developed to support staff.

Sunfield is committed to the ongoing development of evidence-based practice to more appropriately meet the needs of children and young people with ASD. It is widely recognised that early identification of children's needs is of key importance in ensuring the best possible long term prognosis, and in this area the Sunfield Assessment and Outreach Service (SAOS) represents a significant resource. Sunfield provides the same psychology and therapies assessments that inform the approaches used with children through SAOS as a regional service. Following assessment, a tailored support package that may involve consultancy, training and direct intervention work can also be provided.



In such a specific area of practice not all of the answers to our questions are immediately to hand, and so the Sunfield Research Institute plays an important role in supporting the investigation of trends and then feeding into practice. The Research Institute provides support for staff to undertake research projects, as well as undertaking collaborative research with partners.

The Institute is supported by an International Research Advisory Board. Successful strategies identified through research are disseminated via Sunfield Publications, and at a range of national and international conferences. Where appropriate, training courses may be developed to support staff in implementing new approaches identified, and these then offered through the PDC programme and training provided off-site, in venues throughout the UK and also Europe, and recently in New Zealand and Japan.

Current research investigations include:

- Investigating learning environments for children with autism (with University of Worcester)
- Developing social engagement with children with ASD through Sherborne developmental movement (supported by Three Guineas Trust)
- Sherborne developmental movement comparative study between UK and Japan (with Daiwa Foundation, Japan)
- Transition to adult services, and the role of a Transitions Solutions Advisor (supported by Bailey Thomas Fund)
- Supporting children with disabilities to have a self-advocacy voice (supported by BBC Children in Need)
- Exploring the effects of an adapted nutritional approach for children with ASD
- Good practice for children with ASD and visual impairment.
- Developing curriculum resources to support the mental health needs of young peo-

ple with ASD (supported by Partnership for Children)

- Authentic engagement in creativity (supported by a Creativity Action Research Award)
- Siblings perspectives of the future (part supported by RD Turner Charitable Trust)
- Peer Mentoring



If you would like to more about Sunfield's work, please contact us:

Professional Development Centre
(PDC@sunfield.worcs.sch.uk)

Sunfield, APPAAL and SYNAPSIS are collaborating partners of the EAIS project.

New Autism Early Detection Resource:

First signs, Autism speaks and Florida State University's FIRST WORDS Project have developed and launched a web-based ASD Video Glossary to help parents and professionals learn more about the early red flags and diagnostic features of autism spectrum disorders (ASD) .

The Glossary contains hundreds of side-by-side video clips; one of a child who has been diagnosed with ASD and one child who has not been diagnosed with ASD in order for the viewer to notice the difference in the behaviours and reactions of the two children.

The video glossary can be found at either www.autismspeaks.org or www.firstsigns.org and is free to all users.



APPAAL- “1981-2006: 25 years of Autism in Luxembourg”

Association des Parents de Personnes Atteintes d'Autisme de Luxembourg
(Association of People and Parents Suffering from Autism in Luxembourg)

The association was established on 31st May 2000 to respond to a growing need felt by families and by people with autism themselves. The association comprises of a group of parents with a family member who is on the autistic spectrum regardless of nationality.

The Association aims to:

- Uphold the rights of people with autism and the rights of their families, in line with the principles laid down in the 1992 <Charter of people with autism> and the European Parliament's declaration of 6th May 1992 on people with Autism.
- Assist and support people with autism and their families
- Encourage dialogue with the appropriate authorities and back up suggestions by families for appropriate support services for people with autism throughout their life
- Inform the general public so that people with autism can be more effectively integrated in areas such as education, social and cultural life, sport and employment.

APPAAL Project Aims for 2007:

1. An Autism drop-in and information centre: This is so that parents, professionals and the public can have quick and effective access to all available information on autism. It would comprise;

- A specific library
- A selection of teaching material and software (for families using home teaching)
- Workshops for parents on different educational and therapeutic approaches for their children, run by Luxembourgish and international autism experts (educators, psychologists, doctors and therapists)
- Meeting-Point for families: Families need

to be able to meet up outside the home environment, along with their children. Most families are unable to take their children out in public because of the behavioural problems associated with autism. The idea is to enable them to meet up in a calm and relaxed environment so that they can exchange experiences and discuss problems they face on a daily basis with their children.



The Parliament European Politics and Policy Magazine:

The 16th July 2007 issue of The Parliament: European Politics and Policy Magazine is graced with a front cover picture of Kathy Sinnott, Irish MEP, taken at the launch of the EAIS project. Kathy was instrumental in setting up the project. The cover story of the issue was to highlight the plight of autism in Europe.

Kathy mentions how she has tried to bring the lack of knowledge on Autism to the fore in the European Parliament and the European Commission and how there was very little knowledge about this problem despite it being the greatest threat to developing a childhood disability.

Kathy highlighted that while the US were putting billions of dollars into finding out more about Autism, Europe 'didn't have a clue' what was happening. Kathy, whose son Jamie has Autism, began lobbying for the case of Autism and was instrumental in setting up the EAIS project.



In this same issue there is also an article on how the quality of education in the EU varies greatly with many children losing out on the fundamental right to education because they have Autism.

Autism-Europe likewise has an article in this issue where they explain that they are working so that people with autism would have the freedom to develop their own way of life in as independent a way as possible and that people living with autism would benefit from the establishment for service delivery.

How MEPs have a vital role in disseminating information in support of the campaign to create a Europe free from discrimination using effects such as the European Disability forum (EDF) and the campaign to collect one million signatures to draw attention to the plight for rights for people with disabilities, additionally features as part of the cover story.

The SYNAPSIS Foundation:



The SYNAPSIS Foundation which is based in Warsaw Poland, provides professional assistance to people with autism and their families, as well as introductions to system changes, which would improve their quality of life. The foundation was

established in 1990 and has been developing since. The number of people under different kinds of treatment has risen from 106 in 1993 to 375 in 2005. In 2004 the Foundation was awarded a legal status of a Public Benefit Organisation.

The SYNAPSIS Foundation has a range of Activities which include:

Direct assistance provided to people with autism and their families: The foundation conducts diagnosis and comprehensive therapy for children. The activities which take place in the Centre for Children with Autism aim to im-

prove children's health in order to make it possible for them to take part actively and independently in social and professional life. The centre also employs 16 experienced therapists.

Activities for social involvement of people with autism: In 2004, the SYNAPSIS Foundation started the construction of a first model social enterprise in Poland, which will employ people with autism. They are being prepared for work in a social enterprise by a team of 14 therapists.

Professional training of specialists: The Foundation has a highly specialised team of doctors and therapists, who train other people, who professionally help children and adults with autism and their families.

Integration and support of other organisations, which help people with autism in Poland: The SYNAPSIS Foundation initiated the establishment of the AUTISM-POLAND Alliance in 1998 and currently presides the Committee of AUTISM-POLAND, which gathers over 40 organisations acting for the benefit of people with autism in Poland.

Cooperation with centres, which help people with autism in other countries: For a number of years, the Foundation has been a member of a European platform AUTISM-EUROPE. It cooperates with numerous International organisations and institutions, which provide professional assistance to people with autism.

Publications: The Foundation has been issuing publications since 1990. Initially these were mainly books about autism, therapy and education of children from the "OTHER THAN OTHERS" series. With time the foundation started issuing a growing number of publications concerning the advocacy of rights of people with autism. These were Reports about their situation in Poland, guides and periodicals.