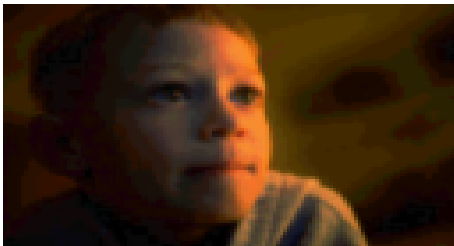




EAIS NEWSLETTER JUNE 2007

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Welcome to the first of a series of quarterly newsletters about Autism Spectrum Disorders (ASD), developed as part of the European Autism Information Systems (EAIS) project. The newsletter will be sent out to Associated Partners, Collaborating Partners and any other interested parties. The contents of the newsletter will include sections on progress of the project, information on meetings, notable events and contributions from partners, which are most welcome. Please contact us at eaais@hopeproject.ie if you would like to contribute or for general enquiries.



WWW.EAIS.EU

The EAIS website has been set up and can be found at www.eais.eu. The mission statement of the project was the forethought while designing the website, making it an easy source for everyone to use.

Our Mission Statement is to “improve the quality of life of children, adults and families affected by Autism Spectrum Disorders (ASD), through early diagnosis of the condition and the creation of a reliable information system on ASD for Europe, which will promote the development of government policies to facilitate appropriate and effective treatments and services.”

In this edition:

- EAIS website
- Pilot Studies Coordination Meeting
- ASD Activities in Spain
- Progress Report from ULSS 20 Verona Italy
- 8th International Congress of Autism— Europe
- New publications from Sunfield

The website is currently being updated and project documents will soon be available to download. News and updates will be posted regularly on the site. A bulletin board is being set up and if you would like to obtain access to this please contact us at eaais@hopeproject.ie.

On the website there are sections which deal with the project activities, those being the European Autism Alliance, the Distance Learning Platform, Public Awareness, Early Detection Tools, Pilot Studies and Autism Surveillance. The website also includes details about all of the partners and their roles in the project. Interested parties can also join the mailing list where they will be updated with information as well as being sent the newsletter.

Pilot Studies Coordination Meeting

A Pilot Studies Coordination Meeting called by Dr Alvaro Ramirez, was hosted by Prof. Martin Knapp in the London School of Economics February 28th 2007.

Parties present included representatives of the project from ULSS 20 Verona, Italy, Aarhus University, Denmark, Instituto Carlos III, Spain, University College Cork, Ireland and King's College London, UK, Autism Cymru, Wales and UCD, Ireland.

A participant from each of the Associated Partners gave a presentation about their work to date and were looking for advice from all participants about the next stages to take in order to complete the project.

Distance Learning Platform –Gillian Ormond, UCC Ireland

It was very important that a case definition is to be set as recommended by EAIS. It was decided that the case definition would be based around the Diagnostic and Statistical Manual of Mental Disorders, Edition four (DSMIV) definition of Autism while taking the International Classification of Disease, Edition 10 (ICD10) and the French definition of Autism into consideration in order to employ the most appropriate definition. A group is to be set up in order to complete the task of developing an EAIS definition of Autism.



Systematic Data Collection Pilot Study –Dr Poul Thorsen, Aarhus University Denmark

It is very important to gather more information from the participating countries on the existing infrastructure and surveillance. There was a discussion concerning inclusion criteria for the surveillance pilot.

Some suggestions were to include whether the diagnosis was clinical or functional, location of the birth, and method of conception (ie. whether IVF was used). It is necessary to have a key person in each area that the pilot is to be run in.

Poland, Czech Republic, Ireland, France, Luxembourg and Spain have expressed an interest in participating in the Prevalence Study and it would be beneficial to involve the same countries in the surveillance pilot. To do this a minimum criteria list is required to ascertain eligibility of pilot areas.

It was suggested that the source of ascertainment of cases would be important for the surveillance study but not for the prevalence study.

A challenge of the project is that not all countries keep a detailed register; as is the case in Denmark, this information in itself can be seen as a result of the study and highlight the lack of information available in European countries.

It was said that it would be an idea to do all of this work online so that it can easily be seen by everyone and checked up. However concerns arose that this may limit the amount of information.

Prevalence Pilot Study Design – Dr Manuel Posada, Carlos III Institute Spain

Results from a primary questionnaire sent to collaborating partners gave a general overview of the situation. It is important to know what proportion of parents of autistic children are in a parents' organisation: for example, 80-90% in Denmark, while in Spain less than 50% of parents are involved in organisations. The issue of data protection was highlighted and whether accurate results can be found due to this, as it could take months for permission to be granted from the data protection agency to access this information.

In Denmark this can be achieved in a relatively short period of time but in most countries there is no surveillance and in special needs schools there may also be an issue with data protection. Following discussions on the use of existing studies, it was agreed that the remit of this project includes carrying out an estimate of prevalence with standard methodology in different countries.

Early Detection – Dr. Maurizio Brighenti, ULSS 20 Italy

Dr Brighenti gave examples of the diagnostic tools, and the areas they explore, most frequently used to detect Autism. The focus is on tools for the age of 24 months or less, on the basis of early detection, excluding tests that are for children older than 24 months. There was a lengthy discussion on the use of different tools for screening and diagnosis of ASD at different ages. Dr Brighenti has found that interactive disorder is the main early warning sign for ASD and is designing a video as an early detection tool, which highlights interactive disorder, to be used by professionals in contact with children such as teachers, public health nurses and GPs. It would also be a tool that can be utilised for raising awareness among parents and professionals. Guidelines are being developed for use with the video which will describe the required structure of a system necessary to identify early warning signs including a description of necessary tools, training and approaches.

Financial Burden Pilot Study – Prof. Martin Knapp, Kings College London, UK

Prof. Knapp gave a presentation on the updated work that had been completed so far, and the tasks that yet have to be completed on the financial burden side of the project. A prevalence estimate is needed by age band, manual work etc in order to be able to describe people by their main circumstances. In order to manage the costs it is easier to work with a smaller number of people.

A recent report was launched on dementia where the prevalence rates were estimated first and then the economic cost was calculated. A retrospective study would normally result in better economic data than a prospective study where a diary is kept to record costs. This may not be the case for parents of children with autism as they might have a large amount of information on hand. A questionnaire would prove more beneficial to collect data as it can be sent out to everyone and it is not a psychometric instrument.

SCIENTIFIC ADVISORY PANEL

Dr Eric Fombonne and Dr Diana Schendel will be asked to review the protocol for the prevalence study. Prof Simon Baron-Cohen and Dr Catherine Rice will be asked to review the early detection tool.

PILOT AREAS/ CALENDAR

It will probably be necessary for Dr Ramirez to visit the pilot areas in order to check that minimum criteria apply and to make final arrangements for the studies. It is important to have a contact or a focal point for all of the pilot areas, clear communication channels and feedback will all be important.



Autism Spectrum Disorder Activities in Spain

Researchers in Autism Spectrum Disorder (ASD) in Spain have formed a multidisciplinary group that was established in 2002 within the framework of rare diseases research projects and collaboration agreements with public health networks and social services systems. This group works in several institutions which include the Research Institute for Rare Disease (IIER), Salamanca University, Madrid Autonomous University, Guipúzcoa Policlínica, Psychiatry service for children at the Hospital Gregorio Marañón, Madrid, and the Ministry of Education, Autonomous Community of Madrid.

Spain is mainly involved in three types of activities related to Prevalence, Surveillance, Screening and Diagnosis of ASD. These are :

1. Research studies and development of new programs:

- A feasibility study of a screening program on Autistic Spectrum Disorders in three different cities: Salamanca , Zamora and Madrid
- A reliability and validity study of the M-Chat in the Spanish Population: Development of a new Spanish version of this questionnaire
- A Case-Control Study in the Spanish Population to see if there is a link between environmental factors and autism.
- Neuropsychological patterns and early social behaviour study in children with ASD recruited by an early ASD pilot screening system
- Developing a Spanish Resources Centre for Research, Training and Support for people with ASD or Pervasive Developmental Disorders (PDD)
- A population screening pilot study using CAST questionnaire for detecting Asperger's Syndrome

2. Diagnosis, Psychological and Educational Support Services:

The main objectives of this institutional resource are:

1. To provide services that include diagnosis, evaluation and multidisciplinary treatment to people with ASD from early childhood to adult life.
2. To guide and support people with ASD and their families.
3. To advise and help to improve the knowledge of professionals and specialists who work with or for people with ASD.

When it is detected that patients have the possibility of a developmental disability they are reported by either health, educational or social professionals. Patients are also recruited from the ASD early screening programs previously mentioned.

3. Training courses on ASD

1. Awareness and capacity building on detecting and diagnosis of ASD: This course is specifically intended for paediatricians, neurologists and psychologists but also for teachers, and other professionals in contact with people with ASD.
2. Daily Life of Adults with Asperger's Syndrome (AS) and High Functioning Autism (HFA): This course is specifically addressed to teenagers and adults with AS or HFA, their families and professionals.

Autism DVD & Photographic Exhibition



“A World Apart – Early Warning Signs in Autism” is the title of a DVD which is to be made by the partners from ULSS 20, Verona Italy. The objective of the DVD is to sensitize the target group to potential cases of autism by highlighting the early warning sign “Interaction Disorder” and to highlight the positive aspects and resources of autistic children. The target groups for the DVD are parents while the second target groups are those in contact with young children such as paediatricians, teachers, nursery school teachers, general practitioners and healthcare professionals in general. The video is to be set in the Autism Centre in Verona which carries out tasks such as diagnosis, treatment and research for subjects with autism and associated disorders from birth to adulthood. The centre is a point of reference in Italy for patients, parents, physicians, teachers and educators who need a clinical response or want to deepen their knowledge in the most recent criteria of intervention.

The film will show a clinical observation to capture the five most important aspects of behaviour that indicate a child might have autism. These aspects of behaviour include isolation/avoidance of the child with the operator and other children, a lack of appropriate facial expression, a lack of eye contact, not responding to their name and not sharing during play sessions. This will be achieved through the filming of 1 or 2 children aged between 18 and 36 months old and by interviewing health care professionals who work with them.

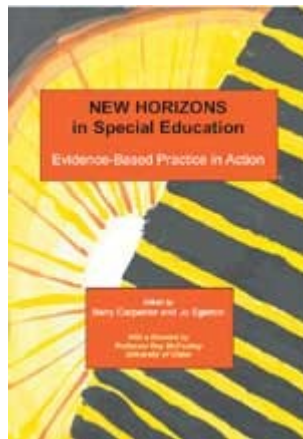
ULSS 20 are also producing a photograph exhibition entitled “This is me !” This is to be a series of black and white portraits of children aged between five and ten years. The photos will capture expressions/behaviour of children with autism in different contexts, including fun activities.

New Publications from Sunfield

Sunfield is an organisation which offers education and 52-week residential care to children and young people with profound autistic spectrum disorders (ASD) and severe and complex learning disabilities. Educating and caring for children with such profound needs challenge established approaches. Sunfield's commitment to evidence-based practice and the need to extend the boundaries of practitioner knowledge have given rise to research projects – both whole school and class-based.

On the 11th and 16th of May 2006, Sunfield is launching two publications – *New Horizons in Special Education: Evidence-based practice in action*, edited by Barry Carpenter and Jo Egerton (£20), and *Moving with Research: Evidence-based practice in Sherborne Developmental Movement*, edited by Liz Marsden and Jo Egerton (£17.50).

New Horizons in Special Education includes chapters describing how to establish a research culture within a school environment, how to make research do-able, and presenting the outcomes of research projects carried out at Sunfield.



Moving with Research includes two chapters describing the adaptation of Sherborne Developmental Movement (SDM) to meet the needs of young people with profound ASD. It also contains chapters from SDM practitioners (including therapists) from the UK and Europe detailing SDM research with different populations, including young people in mainstream education and adults with profound and multiple learning disabilities.



More information about these and other publications is available from:

Tracey Deeley (TraceyD@Sunfield.worcs.sch.uk).



The 8th International Congress of Autism Europe

The 8th International Congress of Autism – Europe is to be held in Oslo, Norway from the 31st of August to the 2nd of September 2007. The congress will be hosted by the members of the scientific committee, Autism Association of Norway.

The motto of the congress is “A World of Possibilities”, while the size of the congress makes it ideal for the development and continuation of friendships both professionally and socially.

The congress will also play host to the 4th International Art Exhibition of People with Autism organised by Autism Burgos entitled “Dialogues in Colour”.

It is believed that the flow of knowledge and interactions possible during this Congress will contribute to improving the everyday lives of persons with ASD and their prospects of leading a dignified life to the best of their potential.

The congresses have always been highly valued as an important opportunity by scientific and clinical professionals, service providers, persons with autism and their parents. They provide an important opportunity to share knowledge and to raise awareness amongst everyone in the community involved with autism about state-of-the-art, evidence-based, practical solutions.

There are three main focal points of the congress:

- State-of-the-art research presented by guest speakers in a series of lectures
- Case studies, diagnostic dilemma's or clinical treatments will be presented at symposia and discussed by experts from different disciplines
- Posters will be organised to link in with the topics of the main sessions

More information can be found at <http://www.autismcongressoslo.org/>



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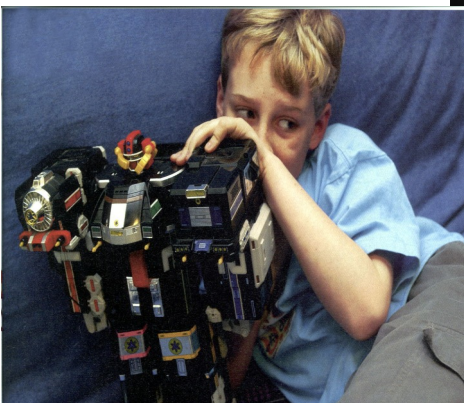
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- Dr Maurizio Brighenti, ULSS 20 Verona, Italy
- Dr Poul Thorsen, Aarhus University, Denmark
- Dr Manuel Posada de la Paz, Instituto Carlos III, Spain
- Ms Mirka Jelínková, Autistik, Czech Republic
- Prof Ivan Perry, University College Cork, Ireland
- Prof Martin Knapp, King's College London, United Kingdom

EAIS COLLABORATING PARTNERS:

- Action Against Autism, Scotland
- Akdeniz University Faculty of Medicine Department of Family, Antalya, Turkey
- APAAL, Luxembourg
- Associazione Siciliana per lo Studio dell'Infanzia, Italy
- Autism Cymru, Wales
- Autism Europe
- Autism Initiatives UK
- Autism Research Co-ordination Group, London, UK
- Autism Rights, UK
- Autism Speaks
- Bulgarian Association of Child Psychiatry and Allied Professions, Sofia, Bulgaria
- CDC Atlanta (NCBDDD - National Centre on Birth Defects and Developmental Disabilities)
- Dr Iva Strnadova, Charles University, Prague, Czech Republic
- Eden Foundation, Bulebel, Malta
- Evald Saemundsen, State Diagnostic and Counseling Center, Iceland
- Irish Autism Action, Ireland
- Instituto Gulbenkian de Ciencia. Portugal
- Kratowe Towarzystwo Autyzmu, Warsaw, Poland
- Le Registre des Handicaps de l'Enfant et Observatoire Périnatal (RHEOP), France
- LOFFA, Ireland

- Mount Carmel Hospital, Attard, Malta
- National Autistic Society, United Kingdom
- PAPA, Northern Ireland
- Pathway Charitable Trust, Edinburgh, Scotland
- Prof Simon Baron-Cohen, University of Cambridge, UK
- Prof Joaquin Fuentes, Policlínica Guipúzcoa, Spain
- Prof Pat Howlin, University of London, UK
- Prof Fritz Poustka, J.W. Goethe Universitaet, Frankfurt, Germany
- Prof Roy McConkey, University of Ulster, Northern Ireland
- Prof Lorenzo Pavone, University of Catania, Italy
- Public Health Authority of the Slovak Republic
- Scottish Society for Autism, Inverness, Scotland
- Sunfield, UK
- Synapsis Foundation, Warsaw, Poland
- Talango Bvba, Brussels, Belgium
- TEPPRA—Terapie Prevenzione Autismo, Acqualagna, Italy
- World Autism Organisation



Source: <http://en.wikipedia.org/wiki/Autism>