European Autism Information System

EAIS-Project

Financing Programme:

Co-financed by DG SANCO European Commission, through the Programme for Community Action in the Field of Public Health (2003-2008)

Associated Partner organizations:

- The Hope Project, UK
- University College Cork, Ireland
- NANEA, Aarhus University, Denmark
- Instituto de Salud Carlos III, Madrid, Spain.
- Institute of Psychiatry, King's College, London, UK
- Centre for Diagnosis, Treatment and Research of Autism ULSS 20 Verona, Italy
- Autistik Prague, Czech Republic

Collaborating Partner organizations:

- 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
- TEPRA—Terapie Prevensione Autismo, Acqualagna, Italy
- World Autism Organisation

Project Timeframe:

January 2006- June 2008

Description of Project (including aims and objectives):

The aim of the EAIS project was to address two areas of deficiency in the European picture, namely lack of systematic, consistent and reliable data on ASD and the lack of agreed and harmonised early detection tools. The action dealt with both issues in a coordinated way by adopting an articulated strategy that included networking among major European stakeholders the scientific community in order to monitor, combat and prevent the condition. Core outputs of this mobilisation were the development of a dedicated information system and evidence based agreement about appropriate diagnostic criteria. The project created a network, the European Autism Alliance (EAA), as a forum to advance the communication and coordination of professional expertise in the EU on ASD. Seminars and Conferences were proposed as methods of reaching Europe-wide agreement on case definition and dissemination of key outputs from the project. A register of concerned professionals has been created to allow greater through flow of communication and opinion. A central aim of the project is to have an agreed information system to record ASD data. This data, recorded in common format across the EU, will provide the strongest, most robust evidence available to determine both the prevalence and financial burden of the disease and to monitor ongoing trends in these areas. After the completion of this project, this system could be further developed as a full scale EU surveillance system.

Role of Inspire (Eden and Razzett Foundation):

The role of Eden Foundation (at the time) was participating on the Second Panel of Experts on Autism as well as having a representative attend meetings held in Luxembourg in September 2007. Eden Foundation's representative, Ms. Doreen Mercieca, contributed to discussions regarding:

1. Case definition
2. Different methodologies have been used in measuring prevalence.
3. A registry system.
4. Comparability within Europe and worldwide.