



NOTE TO HEALTH INFORMATION COMMITTEE

Subject: European actions on Autistic Spectrum Disorders

The term autism spectrum disorders (ASD) is commonly used to refer to the broad umbrella of behaviorally defined disorders termed Pervasive Developmental Disorders by the *DSM-IV* (APA, 1994). These disorders have complex and variable symptoms, along with multiple etiologies, and include: Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, and Pervasive Developmental Disorder, Not Otherwise Specified (PDDNOS).

One of the main difficulties to give estimations about prevalence of ASD, in a historical perspective, is the fact that our understanding of autism has changed over the past decade. One of the changes has been the appreciation that several closely-related disorders exist; they share the same essential features but differ on specific symptoms, age of onset, or natural history. These disorders mentioned above are now conceptualised as ASD. This explains why, according to some published British estimates, the current rates of autism are 16 per 10 000 but in fact these rates increase to 67 per 10 000 when all forms of ASD are included. Debate remains about the validity and usefulness of a broad definition of autism. When large DSM-IV criteria are used, in the most recent studies, prevalence's founded could be on a range of 57.0 to 67.0 per 10 000.

The Work Plans for 2005, 2006 and 2007 for the implementation of the programme of Community action in the field of public health (2003-2008), included a specific reference to the need of information and definition of indicators on Autism/Asperger's Syndrome, cognitive retardation and disruption of motor, perceptual, language and socioemotional functions.

In 2005 the European Commission selected for funding the project 'European Autism Information System'. In the context of the EAIS Project a solid partnership has been established with the American CDC (via the National Centre on Birth Defects and Developmental Disabilities) in order to cooperate to strengthening early diagnosis and to implement and evaluate all available tools and evidence-based arguments, to propose and validate a harmonised tool for early diagnosis of ASD across Europe.

In the 2006 wave of the Public Health Programme a project on a 'European Network for Surveillance of risk factors on Autism and Cerebral Palsy' has been selected for funding. The network will develop guidelines for identification of ASD and CP pre- and perinatal risk factors.

DG SANCO has hosted three meetings of the European Union Panel of Experts on ASD jointly organised by the Unit SANCO C-2 and the EAIS Project, in order to present experience of autism studies in different EU.

A conference grant has been awarded to the European AutismAction 2020: Working Conference on a Strategic Plan on Autism (Dublin 2010) to establish a European strategy to be submitted to the Commission and the Council in the coming years.

Next steps: to implement conclusions of the EAIS Project

Development of a European Autism Alliance

The development of a European network for autism is a key component of the European Autism Information System. The process seems to be completed in 2010.

Characteristics of ASD in Europe

This area of work was fundamental to the overall aim of the EAIS project as it is directly linked to its main objective to develop mechanisms for obtaining systematic, reliable and consistent data on ASD in Europe. This required designing a questionnaire for health care, medical and research professionals and ASD-related associations and institutions that would ensure that relevant information was being provided that would facilitate coherent and comparable analysis.

Design of a European Protocol for Autism Spectrum Disorder Prevalence (EPAP)

As a result of these efforts, a modified questionnaire on health care, educational and social facilities and patients' organisations for ASD was completed. It has also finalised a checklist of criteria for selecting pilot areas for ASD prevalence studies which will assist EAIS collaborating and associated partners in assessing whether or not their country or specific regions or areas in their country would be at an acceptable state of preparedness to participate in a prevalence study in Europe. A proposal will be submitted in the Work Plan 2010.

Measuring the financial burden of ASD

Calculating the financial burden is a complex and complicated process as it needs to take into account a wide range of factors related to the challenge of providing health and other primary and secondary care to individuals suffering from ASD. King's College UK adapted a scoping questionnaire to assess economic burden as part of the EAIS project to address the need for improved knowledge of the impact of ASD in Europe.

Harmonised early detection tool

The issue of early detection, leading to early diagnosis, is a key element in the treatment of children with ASD given that early and intensive education can help children to develop and learn new skills. It is vital for the benefit of the child and her or his parents and family, as well as in reducing the potential long-term cost to the public health system in terms of subsequent rehabilitation and care, to develop early detection tools. The overall objective of this work was to draw up guidelines for early detection on the basis of a comprehensive analysis of existing tools and methodologies.

Action for the Committee:

X	For information
	For comments
	For agreement