

CONGRESO INTERNACIONAL  
SOBRE TRASTORNOS  
DEL ESPECTRO AUTISTA  
AUTISMO BURGOS XXV ANIVERSARIO

“Compartiendo Conocimiento”

Nuevos retos en investigación y calidad  
de vida en personas con Trastorno  
del Espectro Autista (TEA)

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**Title:** ASD prevalence in Europe: A method towards building of na ASD Public Health Policy

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"Sharing knowledeg". New challenges on research and quality of life from people living with ASD

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## **ASD prevalence in Europe: A method towards building of na ASD Public Health Policy**

Autism Spectrum Disorders (ASD) are a lifelong neuro-developmental disorder due to neurobiological conditions (Ritvo ER et al, 1990; Courchesne E et al, 2005). Indeed, ASD are a broad concept that includes phenotypes related with the three main characteristics of autism - early onset of impairments in social interaction and communication and unusual, stereotyped behaviours - as defined by Kanner in 1943.

There is ongoing debate over whether a categorical or dimensional conceptualization is appropriate for ASD. The difficulty of such categorical conceptualization is that the definition of the case may be somewhat arbitrary (Williams et al 2006). Thus, a dimensional conceptualization of ASD is now commonly invoked and a diagnosis is based on the child's developmental history and observations of behavioural patterns across at least two observational settings. In any case, a diagnosis may only be made once symptoms are manifest, sufficient evidence of behavioural symptoms has been gathered and not before 18-24 months of age (Baird et al., 2003).

Incidence studies (Powell JE et al., 2000, Dales L et al., 2001; Kaye JA et al., 2001, Lauritsen MB et al, 2004, Smeeth L. et al, 2004, Barbaresi WJ et al, 2005, Newschaffer CJ et al, 2005, Jick, H, 2006, Taylor B, 2006), although fraught with the difficulties of measuring time of onset of the disorder, have reported an increase in incidence estimates over time. Most, if not all, of the reported rise in incidence and prevalence appears to be due to changes in diagnostic criteria and awareness in professionals (Wing, 2002). However, in 2005, a population based study carried out in Yokohama, Japan provided the first demonstration of incidence increasing (Honda H, 2005a, Honda H, 2005b). In 2007, a study carried out in Denmark showed a statistically significant increase of ASD cumulative incidence across specific birth years (Atladóttir HO et al, 2007). Reasons for this observed pattern of incidence are still unknown but one of the most likely reasons is the early diagnosis accounted during the most recent years.

There has also been considerable variation in prevalence estimates, which may be due either to methodological factors (Medical Research Council, 2001) or to real differences, and two reviews have outlined the methodological barriers to

investigating whether there has been an increase in the prevalence of ASD over time and the possible explanations for the apparent increase (Fombonne, 2002; Wing, 2002). Baird and colleagues (2000), in a study of 16,235 18-month-old children in the South East Thames Health Region, found an estimated prevalence of typical autism of 30.8 per 10,000 (95 percent CI: 22.9–40.6), and of other pervasive developmental disorders of 27.1 per 10,000 (95 percent CI: 19.7–36.4). Bertrand and colleagues (2001) estimated the prevalence of typical autism at 40.5 per 10,000 in a recent study of 8896 3- to 10-year-olds in Brick Township, New Jersey. Chakrabarti and Fombonne (2001) and later on the same authors (Chakrabarti S and Fombonne E 2005), in a study of 15,500 children aged 2.5 to 6.5 years in Staffordshire, England, an estimated prevalence of 62.5 per 10,000 (95 percent CI: 50.8–76.3) for all pervasive developmental disorders was found. The estimated prevalence for Asperger's Syndrome was 8.4 (95 percent CI: 4.5–14.3) per 10,000, and for PDD-NOS was 36.1 (95 percent CI: 27.3–46.9) per 10,000. In one of the few ASD prevalence studies carried out in southern Europe, taking into account the whole population of children between 6 and 9 years old, authors concluded that the prevalence obtained for ASD in children in Portugal was close to 10 per 10,000, (95% CI 8.1–10.0) which was lower than values obtained for the most recent European regional studies. (Guiomar Oliveira G, 2007)

A systematic review of prevalence studies has contributed to explaining some of the influences on variation among prevalence estimates. Over half of the variation among study estimates can be explained by the age of the children screened, the diagnostic criteria used, and the country studied. Other important factors were whether the study was in a rural or urban location and whether cases were assessed prospectively or retrospectively. The impact of these known factors on prevalence estimates should now be further investigated as they may be acting as proxies for other influences on prevalence. For example, the effect of geographical location on prevalence may be due to the services available, or variation in awareness of the disorder (Williams JG et al., 2006).

One of the most recent publication on prevalence is from a study carried out by the CDC in 2002 (Kuehn BM, 2007, Rice CE et al, 2007, Van Naarden Braun K et al, 2007).

This study included approximately 10 percent of U.S. eight-year-old children born in 1994 from 14 states. A total of 407,578 children were involved and 2,685 eight-year-olds were identified as having an ASD.

The previous study by CDC, developed in 2000, found ASD rates ranged from one in 222 children to one in 101 eight-year old children in the six communities studied. The 2002 study found ASD rates ranging from one in 303 to one in 94 among eight-year old children. The average finding of 6.6 per 1,000 eight-year-olds translates to approximately one in 150 children in these communities. This is consistent with the upper end of prevalence estimates from previously published studies, with some of the communities having an estimate higher than those previously reported in U.S. studies.

Whatever prevalence study could be developed, it is necessary to point out that “valid estimates of the incidence or prevalence of ASD require studies that meet five criteria: 1) a base population of sufficient size to provide a substantial number of individuals with an ASD (so that the confidence interval will be narrow); 2) a defined epidemiological population that covers all the individuals likely to be at risk for an ASD; 3) systematic standardized screening of the total population; 4) a focus on an age group for which it is known that diagnostic assessments are reliable and valid; 5) diagnosis by trained professionals using high-quality standardized research assessments” (Rutter, 2005). Beside these points, there are different types of ascertainment methods. There are methods for ascertainment where there is very little infrastructure to work with, this is often the case in developing countries; the second is a registry-based approach, which may include linking to biobanks and the third is a service and records-based approach.

### **EAIS and European Actions**

One of the areas addressed by the European Autism Information System (EAIS) project has been the lack of systematic, consistent and reliable data about prevalence and trends on ASD in Europe.

In July 2006, an ad hoc questionnaire was developed within the EAIS project for improving our knowledge about the characteristics of whatever health, education, social or parents' organization services, devoted to autism, exist in those countries where the European project is being carried out. This questionnaire also included a section that summarizes the probability of data access in each of the services analyzed. The most important conclusions from this survey are,

- It is not clear whether we could get data directly from either health or educational services, except in those countries with an active population registry.
- There are many sources that could provide ASD cases.

This project also developed the European Protocol for Autism Spectrum Disorder Prevalence (EPAP) attempting to harmonize future methodological issues concerned with these types of study designs. This protocol is based on a stepped approach, comprising three different phases: Stage 1 (*identification of potential cases*), Stage 2 (first approach to diagnosis) and Stage 3. (confirmation of the diagnosis). As a typical epidemiology study some other points such as setting, design, population, case definition, inclusion criteria, sources of information, case ascertainment and procedures, data collection, instrumentation, quality of diagnosis and reliability analysis, biological investigations, statistical analyses, difficulties and limitations, ethical issues, expected results and added value of European cooperation and references are included.

### **Justification of the need to measure European ASD prevalence**

There is no cure for autism, but research on the efficacy of early, intensive behavioural interventions suggests that developmental trajectories can be positively altered, particularly with respect to language and cognitive development (Crane JL and Winsler A, 2008, Dawson G and Osterling, J, 1997, Ozonoff S and Cathcart K., 1998, Rogers SJ.1998). This is why, whatever the causes of the rise in prevalence, it is a reality that we now have more cases diagnosed during childhood and adolescence that need care, attention and treatment. This is not exclusively a matter of social justice and/or equity

but it is a question of capacity building for bearing the tremendous burden that families and society are going to have to continue accepting if we do not now adopt the necessary decisions for improving the social and communicative capacities of these children and teenagers. Prevalence is also an important estimate for burden of diseases analysis and for policy-making decisions. In fact, prevalence and some other related measurements are used for defining and designing health, educational and social resources (Rice CE et al, 2007), but the social and economic burdens of ASD have not been adequately recorded as epidemiological figures were, except in some specific situations (Jarbrink K. and Knapp M, 2001, Sanchez-Valle E et al, 2007).

Moreover, if an increasing prevalence is a reality, incidence would have been rising during the previous years, and a real concern about improving research for environmental causes should be incorporated into autism research policy decisions.

#### **Towards a European Public Health Action on ASD**

Focus on early identification and prevalence is critical in establishing public health responses and in ensuring appropriate support and treatment for affected children and their families. At a time of growing European integration at all levels and in all areas, including knowledge management in and between public health systems, it would be important that member States can learn from each other's experiences and research and share key information and systems, particularly from those countries which have already established public health responses to ASD. In addition, European member States should look beyond the boundaries of the European Union (EU) to create alliances and partnerships with relevant institutions in other parts of the world which have also been studying ASD and elaborating appropriate public responses, particularly in the USA where there has been considerable research and advances in this field.

The ongoing lack of understanding and coherence surrounding ASD has exacerbated the difficulties facing those children and their families in accessing adequate and appropriate public services, including health care and medical treatment and education and social support.

Since 2005, ASD has been included in both the 'Rare Diseases' and 'Major and Chronic Diseases' Task Forces of the European Commission (EC). Although some conditions or syndromes within the autism spectrum can be categorised as rare diseases, there is an argument for no longer categorising ASD as such. Indeed, the public health burden of these disorders is now a considerable one. As early as 1996, the European Parliament launched an official declaration in which it urged the EC to fully support any effort and project to develop the rights of people with autism.

**'European Autism Action 2020'** is a strategic plan of actions with two main objectives: the first is to ensure a minimum standard of public services in education, health, specialist speech therapy and respite care for all people and families affected by ASD across EU members and applicant countries by the year 2020. The second objective is to improve knowledge and understanding on treatment, risk factors and prevalence of ASD in EU member states and applicant countries for the year 2020.

Four lines of integrated action can be defined in order to achieve these objectives:

- Partnership and Services
- Integrated Research Strategies
- Awareness, education and EU Policies
- European Autism Information System (EAIS)

#### **Initial steps to be taken 2009 – 2010**

Preparation of European Autism Action (EAA) 2020 will start with a consultation process with the most relevant experts on autism in Europe and abroad during 2009. Following sub-regional consultative meetings, a working conference is planned for 2010 to establish terms of reference for a ten-year strategic plan to achieve the objectives mentioned earlier. Irish Autism Action (IAA) will be the lead organisation in the preparation and promotion of the EAA2020. To ensure the participation of relevant stakeholder organisations and scientific experts in the sub-regional meeting and 2010 conference is an important action for the remainder of 2009.

DG-SANCO, as well as IAA's own resources have confirmed their commitment to funding this initial step. At the same time, some other European projects, focused on

building an ASD registry and promoting early diagnosis, are also activities to be implemented in the near future.

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