



**European Autism Information System (EAIS)  
Report on the 'Autism Spectrum Disorders Prevalence  
Data and Accessibility to Services' Questionnaire (Q-  
EAIS)**

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## **Background**

Autism Spectrum Disorders (ASD) are a group of lifelong neuro-developmental disorders due to neurobiological conditions (Ritvo ER et al, 1990; Courchesne E et al, 2005). ASD typically refer to 3 (Autistic Disorder- AD, Asperger Syndrome- AS and Pervasive Development Disorder Not Otherwise Specified- PDD-NOS) of the 5 Pervasive Developmental Disorders which also include Rett's Syndrome and Childhood Disintegrative Disorder (APA, 1994; Szatmari P, 2000). Different factors have been suggested as potential causes for autism. Genetic factors are probably the most influential although malformations (Szatmari P. et al., 2007), inborn metabolic errors (Filipek PA et al., 2000), external causes such as chemical exposures (Newschaffer CJ et al., 2002), perinatal complications (Glasson EJ et al., 2004) and side effects from virus infectious, among others have been also suggested.

DSM-IV-TR and ICD10 are the two major international classifications that provide criteria for ASD diagnosis (American Psychiatric Association, 1994; World Health Organization, 1993; Howlin and Moore 1997). Although there are some overlaps between them, DSM-IV is probably more used for clinical diagnosis than the ICD10.

There is ongoing debate over whether a categorical or dimensional conceptualization is appropriate for ASD (Williams JG et al 2006, Williams J et al, 2006) but a dimensional conceptualization of ASD are 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, and sufficient evidence of behavioural symptoms has been gathered (Baird et al., 2003).

Prevalence of ASD as a combined group is substantially greater than previously recognised, for example, a study carried out in Denmark showed a statistically significant increase in cumulative incidence of reported ASD diagnoses across specific birth years (Atladóttir HO et al, 2007), but reasons for this observed pattern is still unknown. ASD prevalence is generally accepted as ranging from 45 to 67 cases per 10,000 (Atladóttir HO et al, 2007) but the most recent papers show an increase in prevalence estimates raising figures of up to 116.1 cases per 10,000 children (Kuehn BM, 2007, Rice CE et al, 2007, Van Naarden Braun K et al, 2007, Baird G. et al.2006). This variability may be due either to methodological factors (Medical Research Council, 2001) or to real differences, which is challenging to disentangle since ASD are defined by patterns of behaviours.

A systematic review of prevalence studies has contributed to identifying some of the influences on variation among prevalence estimates (Williams JG et al., 2006). In the review, over half of the variation among study estimates could 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 availability of services or variation in awareness of the disorder. By taking this quantitative approach, it was shown that using meta-analytic techniques can be a valuable additional tool in deepening our understanding of the influences of study and population characteristics on variation in prevalence estimates in ASD (Williams JG et al., 2006).

In February 2005, the European Commission for Health and Consumer Protection Directorate-General stated the following conclusions on ASD:

- the EU lacks good data to test hypotheses on secular changes in the incidence of autism. Because of specific methodological limitations, the high prevalence rates reported in recent autism surveys in the EU and in the USA cannot be used to derive absolute conclusions on this issue.
- An ASD response policy is necessary in the EU.
- More complex monitoring systems than those currently in place are needed to address the issue of changes in the prevalence of ASD.

In addition, on 5<sup>th</sup> June 2004, the European Commission, by way of oral answer to Kathy Sinnott MEP (Ireland) stated that there was ‘no comprehensive or comparable data at EU level concerning the incidence or prevalence of this disease’ and further stated that it would welcome project proposals in the area of autism. In response, a network of professionals and stakeholders concerned with ASD, the European Autism Alliance (EAA), drew up the European Autism Information System Project (EAIS) supported by EU funding. The EAIS Project proposal included several aims related to understanding the population of people affected with an ASD in the EU.

The central aims of this first phase of the “*Strategy for the Development of an ASD Prevalence Estimate within the framework of the EAIS project*” were to:

- Improve the knowledge of characteristics of the ASD services related to public health, educational system, social services and/or parents’ organizations existing in those countries where the EAIS project is being carried out and to find out the pathway that people with an ASD need to follow to access these services.
- Obtain information about the data access difficulties that could be found in ASD prevalence studies when these studies are developed at European countries.

## **Methods**

In July 2006, an ad hoc questionnaire (Q-EAIS) was designed within the framework of the EAIS Project by the ASD Study Group of the “Research Institute for Rare Diseases” in Spain. The questionnaire was intended to provide a systematic survey of resources which may be relevant to understanding the population of people affected with ASDs in the participating EAIS Project countries. The questionnaire was targeted for regions (also national information) where the EAIS partners are situated.

### **Questionnaire description**

The questionnaire was broken down into six different sections. Four of these sections sought to explore the organization and situation of the health, educational and social services as well as a description of parents’ organizations in the [region / country]. The other two sections focused on general aspects of diagnosis, follow-up and access to data. A total of 65 different questions complete the survey. Closed questions from a simple model of answer such as yes/no to models including several options were used. There are also questions constructed as tables  $n \times n$  where many options are available. Finally, open questions are also used for general comments and descriptions. Distribution of questions and its order is shown in Table 1.

**Table 1: Distribution and order of questions in the Q-EAIS**

Type of questions	Questions order	Number of questions	Number of open questions
ASD diagnosis	1 to 19	19	7
Health care services	20 to 28	9	2
Education services	29 to 45	17	5
Social services	46 to 54	9	3
Parents' organisations	55 to 60	6	1
Access to data	61 to 65	5	1

Questions on services for detection and diagnosis criteria and average age of diagnosis constitute the first section. The second section deals with health services and explores the main characteristics of both private and public health services, the well child surveillance programme, health reference centres, ASD registry, type of data stored and data access.

The educational service section comprises general questions on the public education system, age range for starting and finishing compulsory education, different schooling patterns for ASD (inclusive education, integration, and separate education) and special schools for children with ASD. The social services section collects information on early intervention, respite programs, speech therapy, accessibility and waiting lists for both private and public services.

There is a section with questions on the parents' organizations that explores the number in each country, what services they provide and how many families are members. Even though a particular section for data accessibility has been included, all previous sections have specific questions about accessing data. Authorities indicate whether they gather data regarding all ASD diagnosis or not and, if positive, what kinds of data they gather, whether there is any public database in education where all the information regarding children attending public or private schools is gathered and what kind of documentation on ASD is available. It also includes questions about whether there is a Case Registry of ASD as well as epidemiological studies and centres responsible for them. To finish, there is a question about the nature of access to the database by the ASD organizations in each country.

### **Preliminary considerations**

A total of 18 EAIS project partners with capacity to report on their respectively countries or regions of influence received this questionnaire.

This study was carried out with the intention of considering each participant geographical area as an individual and unique problem from the point of view of conducting a population-based prevalence study. For this reason, the report is descriptive and combines aggregated data with individual information from each partner. In other words, the information provided by this report should be seen from the responders' own perspectives. However, the possible lack of partner information for a particular question or some small differences within the region explored not initially considered by the responder cannot be ruled out. This report aims to take into account a critical analysis of the situation of each one of the participants.

## **Results**

### **Participant countries**

A total of 11 questionnaires have been collected until now (Bulgaria, Czech Republic, Denmark, England, France, Italy, Malta, Poland, Portugal, Scotland Highland Region and Spain). Seven responders referred to the whole country and four to their region of influence exclusively.



**Table 2: Partners' information**

Type of EAIS region involved	Country	Respondent's name and internet details	Organisation/ institution	Main activities
<b>Countries</b>	<b>Portugal</b>	Guiomar Oliveira and Ms Astrid Moura www.chc.min-saude.pt	Paediatric Hospital of Coimbra (INSARJ)	ASD Governmental Epidemiology Research team
	<b>Malta</b>	Dr Paul A Bartolo www.theedenfoundation.com	Eden Foundation	NGO for people with disabilities
	<b>Czech Republic</b>	Miroslava Jelínková www.autismconsulting.com	Autistik NGO	Parents' organization
	<b>Poland</b>	Agnieszka Rymsza en.synapsis.pl	Synapsis Foundation	Therapy centre for autistic children
	<b>Bulgaria</b>	Dimiter Terziev M.D. dislter@yahoo.co.uk	Bulgarian Association of Child Psychiatry and Allied Professions	Professional association
	<b>England</b>	Richard Mills www.nas.org.uk	National Autistic Society (NAS)	Registered charity, provides education and care for people with ASD across the UK
	<b>Denmark</b>	Poul Thorsen www.nanea.dk	North Atlantic Neuro-Epidemiology Alliances (NANEA)	Health science research ASD population registry
	<b>Spain</b>	Manuel Posada iier.isciii.es/autismo	Instituto de Salud Carlos III	ASD Governmental Epidemiology Research team
<b>Regions</b>	<b>Veneto, Italy</b>	Maurizio Brighenti www.ulss20.verona.it	Centre for Diagnosis, Treatment and Research of Autism, ULSS 20	Diagnosis, treatment and research for ASD
	<b>Rhone-Alpes/Isère, France</b>	Guillaume Pascale www-rheop.ujf-grenoble.fr	Registre des Handicaps de l'Enfant et Observatoire Périnatal de l'Isère et des 2 Savoie	ASD population registry
	<b>Highland Region, Scotland, UK</b>	Carolanne Mainland www.autism-in-scotland.org.uk	Scottish Society for Autism (SSA)	Registered charity for people with ASD and families

**Socio-demographic characteristics of the responder countries**

The group formed by the eleven responder countries comprises 290.1 million of inhabitants (63.1% of the EU-25). Six of them were referring to the whole country such as Portugal, Malta, Poland, Bulgaria, Czech Republic, England and Denmark covering a total of 122.9 million (26.7% of the EU-25) while the other four are referring to particular regions from countries such as Spain, Italy, France and Scotland Highland Region. The latter group would cover 167.2 million inhabitants (36.4% of the EU-25) (see Table 3).

**Table 3: Distribution of the population among countries participants**

Country	Total population 0-14 years (%) (million)	Population (million)	Net migration rate
<b>Bulgaria</b>	1.07 (13.8)	7.8	<b>7,246</b>
<b>Czech Republic</b>	1.52 (14.9)	10.2	<b>36,229</b>

<b>Denmark</b>	1.01 (18.8)	5.4	<b>6,734</b>
<b>Spain</b>	6.,23 (14.5)	43.0	<b>641,199</b>
<b>France</b>	11.21 (18.5)	60.6	<b>205,115</b>
<b>Italy</b>	8.25 (14.1)	58.5	<b>324,211</b>
<b>Malta</b>	0.07 (17.6)	0.4	<b>952</b>
<b>Poland</b>	6.38 (16.7)	38.2	<b>-12,878</b>
<b>Portugal</b>	1.63 (15.6)	10.5	<b>38,400</b>
<b>United Kingdom</b>	10.92 (18.2)	60.0	<b>NAD</b>
• <b>England</b>	9.02 (17.9)	50,4	<b>NAD</b>
• <b>Scotland</b>	0.86 (16.9)	5,1	<b>193,314</b>
<b>All participants</b>	47.28 (16.3)	290.1	<b>1,402,160</b>
<b>EU-25</b>	75.42 (16.4)	459.9	<b>1,776,284</b>

**NAD:** No Available Data

**Net migration per 1,000:** The difference between immigration into and emigration from the area during the year (net migration is therefore negative when the number of emigrants exceeds the number of immigrants). Since most countries either do not have accurate figures on immigration and emigration or have no figures at all, net migration is estimated on the basis of the difference between population change and natural increase between two dates.

The age gender distribution published in EUROSTAT comes from the year 2003. The proportion of females is higher than males in medium and older ages but not in children. The number of males is higher in the ages of interest: from 5 to 14 years. In Table 4, some health and educational indicators are shown. There is certain homogeneity among most of the fertility rates, infant mortality rates and number of live births. The excess of mortality rate could hide a bias in the case a prevalence analysis is conducted. Most countries reported education participation rates at age of four years close to or equal to 100 %, while at the other end of the range, less than 50% of children aged four years old were at school in Poland. These data show us that this source of information will be not valid to conduct a harmonized prevalence population study based on children under four years old in all of these participant countries.

**Table 4: Distribution of health and educational indicators among participants**

<b>Country</b>	<b>Total fertility rate</b>	<b>Infant mortality rate</b>	<b>Live births per 1,000</b>	<b>% 4 years participation in education</b>
<b>Bulgaria</b>	1.31	10.4	71.1	73.2
<b>Czech Republic</b>	1.28	3.4	102.2	91.4
<b>Denmark</b>	1.80	4.4	64.3	93.5
<b>Spain</b>	1.35	3.8	466.4	99.3
<b>France</b>	1.94	4.0	80.8	100.0
<b>Italy</b>	1.31	3.9	554.0	100.0
<b>Malta</b>	NAD	6.0	3.9	94.4
<b>Poland</b>	1.24	6.4	364.4	38.1
<b>Portugal</b>	1.4	3.5	109.3	84.0
<b>United Kingdom</b>	1.78	5.1	722,5	91.8
• <b>England</b>	1.80	5.0	613.0	100.0
• <b>Scotland</b>	1.62	5.2	54.4	100.0

**NAD:** No available data

**Fertility:** The mean number of children that would be born alive to a woman during her lifetime if she were to pass through her childbearing years conforming to the fertility rates by age of a given year. It is therefore the completed fertility of a hypothetical generation, computed by adding the fertility rates by age for women in a given year (the number of women at each age is assumed to be the same).

**Live births per 1,000:** Live births are the births of children that showed any sign of life (total births minus stillbirths).

**Infant mortality per 1,000 live births:** The ratio of the number of deaths of children under one year of age during the year to the number of live births in that year. The value is expressed per 1,000 live births.

## Descriptive analysis of the Q-EAIS

### *Description, detection and diagnosis*

Results of the questions relative to detection and diagnosis for ASD (Table 5) show that 45% the countries use both ICD10 and DSM-IV TR standard definition; 36% declare to use DSM-IV or ICD10 uniquely; as an exception France uses its own classification (CFTMEA-R2000) besides ICD10. Every country includes “Autistic Disorder” and “Asperger’s Disorder” as subtypes for ASD diagnosis and all but Malta use also “PDD-NOS”. “Rett Syndrome” is included in 81% of the countries and Childhood Disintegrative Disorder (CDD) in 27%. Most countries declare ASD as a medical or psychiatric condition and only in High Scotland it is declared to be considered mainly psychological and educational in children (psychiatric in adults) and to have little awareness of underlying biological and environmental influences.

Every country declared that ASD cases are mainly detected at the Public Health Care System (PHS) (54% often or very often detected at PHS and 45% only sometimes). Regarding diagnosis, it is mainly given by PHS (100%), most of them in the regional or national reference centre or hospital for ASD diagnosis (72% of the countries declare to have one of that centres) and in some cases by the private centres or ASD parents’ organizations (27%). In these cases, families can get reimbursement (totally or partially) of the diagnosis expenses although not always. The final decision depends on the service and the existence of a previous agreement with public authorities.

The age at which diagnosis of autism is obtained varies depending on the subtype but the averages and most common answers are: 3-4 years old for AD (72%), 5-6 years old for AS (36%) and 3-5 years old for PDD-NOS (the other answers were very variable). Every participant country except Malta stated that they have PHS universal coverage. 45% of the countries declare to have a well-child surveillance protocol after 18 months and 54% declare to have an established protocol at the Public Health System (PHS) for ASD early detection.

**Table 5: Description, detection and diagnosis**

<b>ASD Description</b>	<b>Number of countries</b>
<i>Standard definition</i>	
• DSM-IV TR (only)	2
• ICD-10 (only)	3
• Both	5
• ICD-10+Other	1
<i>Subtypes included</i>	
• AD & AS	11
• PDD-NOS	10
• Rett syndrome	9
<i>ASD as ... condition</i>	
• Medical or psychiatric (with other repercussions)	10
• Psychological/educational	1*
<b>ASD Detection, Diagnosis and Diagnosis Services</b>	
<i>Mainly detected/first recognized</i>	
• Public health care system	11
• Educational system	5
<i>Mainly diagnosed</i>	
• Public health care system	11
• Also diagnosed by private professionals parents’ organizations	2
<i>Age of diagnosis</i>	
• AD (3-4 years old)	8
	4

<ul style="list-style-type: none"> <li>AS (5-6 years old)</li> <li>PDD-NOS (3-5 years old)</li> </ul>	<b>3</b>
<i>Other useful information</i> <ul style="list-style-type: none"> <li>Reference centre for ASD diagnosis</li> <li>Countries with protocol for early detection of ASD</li> <li>Well-child Surveillance Protocol after 18 months</li> <li>Monitoring Prevalence Data</li> </ul>	<b>8</b> <b>6</b> <b>6</b> <b>2***</b>
<p>(*) Malta considers that ASD is an educational/psychological condition for children and psychiatric for adults.  (**) 9 countries declared that most cases were diagnosed by public health, but those countries also declared to have many cases diagnosed by private professionals.  (***) France and Denmark are able to offer prevalence results but in some regions of England some prevalence studies have been already carried out (see also Table 8).</p>	

There were differences among countries regarding the General Education Services (Table 6, section 1). 81% have a compulsory education system starting before 6 years of age. Six countries declared that most children attend preschool centres and 5 stated that they do not have available data. 63% of the countries declared to have special education needs (SEN) units specifically meant for children with ASD: 25% of them declared to have them only public centres and 37 % to have different types of SEN units (public, private, private non-profit subsidised and managed by support groups). Portugal, High-Scotland and Italy declared not to have ASD SEN units.

Regarding the Educational Services (ES) for children with ASD (Table 6, section 2), only 4 countries declared that all children with ASD participated in public education programs. In the rest of the countries, most children with ASD are trained at home (54%) and some also in social services and /or private therapies (27%). Most (81%) of the countries stated that they have an inclusion model among their SEN schooling patterns but at the same time, 7 countries (included among the 9 who declared inclusion) declared to have also separate education (special schools and mainstream schools) in the same countries. The range 19-20 years is the oldest and most frequent age for ASD students to stay at school.

**Table 6: Education system**

	<b>Number of countries</b>
<b>General education services</b>	
<i>Compulsory education starting</i>	
<ul style="list-style-type: none"> <li>5 years old</li> <li>6 years old</li> <li>7 years old</li> </ul>	3 6 2
<i>Pre-school centres</i>	
<ul style="list-style-type: none"> <li>Most children attend</li> <li>Non available data</li> </ul>	6 5
<i>Special Education Needs (SEN)</i>	
<ul style="list-style-type: none"> <li>Public (only)</li> <li>Private non-profit subsidised (only)</li> <li>By parents' support groups (only)</li> <li>All types</li> <li>No facilities</li> </ul>	2 1 1 3 3
<b>Children with ASD</b>	
<i>Participation mainly in:</i>	
<ul style="list-style-type: none"> <li>Public education programmes</li> <li>Home education</li> <li>Social services</li> <li>Private therapies</li> </ul>	3 6 2 1
<i>Age they stay at school</i>	
<ul style="list-style-type: none"> <li>16-18</li> <li>19-20</li> <li>21</li> </ul>	2 3 1

<ul style="list-style-type: none"> <li>• It depends on the needs</li> <li>• NA</li> </ul>	<p>2</p> <p>3</p>
<i>Schooling patterns</i> <ul style="list-style-type: none"> <li>• Inclusion</li> <li>• Integration</li> <li>• Combined or multi-track option</li> <li>• Separate</li> </ul>	<p>9</p> <p>8</p> <p>6</p> <p>7</p>

Once the child has received an ASD diagnosis, there are some public institutions responsible for providing different social services (Table 7). Most of the countries declared to have early intervention services (81%) and speech therapy and that families can receive economical support, and family-counselling education (72%). 63% declared to have respite programmes and social work services in cases of poverty and 36% to have case management (coordination of all services provided). However, only 30% affirmed that all of these services meet demand opposed to Portugal that only has early intervention and follow-up services and not other social services public system but despite so they declared these services meet demand.

In 81% of countries surveyed, the accessibility to these services depends on fulfilling certain requirements (income, residence, disorder severity) and only one country is able to claim that the average waiting time for receiving services from when the family has applied for them is less than a month, 27% confirm that the same process takes from 1 to 3 months or 3 to 6 months (27%) and the rest say this time is highly variable in their area.

All participant countries have at least one national parent support group or patients' organizations for ASD. It is declared that in 4 countries, these organizations provide diagnosis and intervention services, in 3 countries they only provide intervention (Bulgaria, France and Portugal) and in 3 countries (Malta, Czech Republic and Italy) these organizations do not provide any services in their area (Table 7). Denmark does not provide any data regarding this matter. Five countries declared that more than 50% of their families belonged to one of these organizations.

**Table 7: Characteristics of the social services and parents' organisations in participating countries**

	Number of countries
<i>Social services</i>	
<ul style="list-style-type: none"> <li>• Economic support</li> <li>• Individual or speech therapy</li> <li>• Social work services</li> <li>• Early intervention (0-3 years old)</li> <li>• Domestic/Household support, respite programmes</li> <li>• Individual therapy</li> <li>• Speech therapy</li> <li>• Family education/counselling.</li> <li>• Follow-up services</li> <li>• Physical therapy</li> <li>• Case management</li> </ul>	<p>9</p> <p>8</p> <p>6</p> <p>7</p> <p>6</p> <p>8</p> <p>8</p> <p>6</p> <p>7</p> <p>6</p> <p>4</p>
Social services meet demand	3
Users' access to services depends on certain requirements*	7
<i>Time from the family demand until they receive the service</i>	
<ul style="list-style-type: none"> <li>• Less than a month</li> <li>• 1-3months</li> <li>• 6-12 months</li> <li>• Highly variable</li> </ul>	<p>1</p> <p>3</p> <p>3</p> <p>4</p>
<i>Services provided by national parents' organisations/groups for ASD</i>	
<ul style="list-style-type: none"> <li>• Intervention (only)</li> </ul>	3

• Diagnosis and intervention	4
• None	3
* Other requirements than ASD diagnosis	

### *Data access*

91% of the respondents declare that PHS authorities gather ASD data (only when the person has been diagnosed in a public centre). 45% of the countries declare to have evaluation records and reports in ES though 72% declare to have public databases in ES (Table 8). The ASD data availability in the educational services varies among countries regarding whether they gather the following kind of documents: educational and occasional monitoring visits (9%), medical or psychological data (18%), and diagnosis (27%).

In the same way, only 27% declare that also data of children who attend SEN units, with other diagnoses than ASD, would be available in the ES in order to identify other possible cases of ASD (1 country state that they do not gather this data in ES and 7 countries do not answer). 54% countries declared that the institution in charge of giving the disability certificate also keeps ASD data regarding diagnosis. About whether they consider that the databases of the ASD organizations are accurate or not, only 3 respondents answered affirmatively and they did not specify type of data gathered.

**Table 8: ASD data accessibility**

	<b>Number of countries</b>
<i>Health service data</i>	
• Authorities gather ASD data (either in a public or private service)	9
<i>Education services data</i>	
• Evaluation records describing symptoms for ASD	5
• Public databases	8
• Accessibility to information on children with SEN and no diagnosis of ASD	3*
<i>Social services data</i>	
• Institution issues a disability certificate and gathers ASD data	6
ASD organisations	
• Reported as accurate databases	3
* 7 respondents did not provide any information on this issue	

Six countries (Portugal, Scotland, France, England, Czech Republic and Denmark) stated that an ASD prevalence study of diagnosed ASD cases has been, or is currently being developed in their country/region. Every country shows each own case ascertainment procedure and prevalence results (Table 9) which indicates the need of a common framework in Europe. Bulgaria, Spain, Italy and Poland have other possible data sources (hospital records, charts, databases of parents' organizations, among others, but not real registries) that might be available for a prevalence study. Malta did not provide this sort of information.

**Table 9: Countries involved in ASD prevalence studies**

Country	Conducted by	Subjects age	Study years	Case ascertainment	Prevalence results
<b>Czech Republic (14 districts)</b>	Ministry of Education	Whole range	2000	None	Prevalence results show big differences in separate districts. The data are not fully relevant. It was only an attempt to estimate which services in the area of education are needed.
<b>Scotland (Highlands region)</b>	Public health	0-19 years old	Pre-2000	No clear verification method. ASD mapping and planning group set up as a result.	Current results with new robust criteria - about 400
<b>France (Department of Isère)</b>	RHEOP	7 years old	1980-1993	French classification used by psychiatrists	22.2 per 10,000
<b>England (South London)</b>	Wing And Gould	0-5 years old	NAD		NAD
<b>Denmark</b>	Several contributors, e.g. Marlene B. Lavritson	NAD	NAD	Psychiatrists	4-5 per 10,000
<b>Portugal (Oliveira et al., 2007)</b>	Guiomar Oliveira	9-10 years old	1999-2000	Population-based study and education survey.	9.2 per 10,000 on the mainland and 15.6 per 10,000 in The Azores

\* NAD: No available data

There are five countries (England, Scotland, France, Italy and Denmark) that have a case registry and all of them except England have a centre responsible for it. In three of them (England, France and Denmark) the registry is compulsory and identifiers are maintained within the registry. It is important to point out that Denmark is the only country having an ASD national case registry.

27% report that they would be likely to get ASD data from the public health system. Similar information would be available from public ES and/or public SS (45%), private educational services (9%) and from ASD organizations (72%). It is important to point out that 81% of the respondents stated that general laws, regulations or permissions apply to the collection of ASD identifying information, even though most have a Data Protection Act.

**Table 10: ASD epidemiology in participating countries: Registry and prevalence studies**

Questions	Number of countries
<b>Case registry</b>	6
<i>Types</i>	
• National	1
• Regional/local/provincial/county	5
<i>Characteristics</i>	
• Compulsory reported cases (if parents do not refuse)	3
• Voluntary reporting	1
• Identifiers maintained	4
<b>ASD prevalence study</b>	5

<b>Likely to get data for a prevalence study</b>	<i>Health</i>	<i>Education</i>	<i>Social</i>
• Public (only)	3	6	5
• Private (only)	0	1	0
• Both	0	2	0
• ASD parents' organisations	8		
<b><i>Laws and regulations for collecting ASD data</i></b>	9		

## **Analysis by country**

Just by taking the answers in the questionnaires at face value and without making any judgement, the information in the Q-EAIS provided notable qualitative impressions of ASD services and accessibility to data in each country, in addition to the quantitative data presented above. The following summaries are intended to illustrate this point. Some of the content is a direct transcription of comments given by participant countries in the questionnaire.

### **Czech Republic**

ASD is commonly classified as a psychiatric condition. There is not enough information about autism among doctors of the first contact (paediatricians and GPs), and children with ASD very often have a wrong diagnosis (ADHD, mental retardation, behaviour problems). Besides the public health authorities do not always gather data regarding all ASD diagnosis (depends on the diagnostic service and the kind of agreement with it).

The official body or institution in charge of deciding which is the most appropriate educational plan for children with SEN is the Social Services Counselling centres for children with special educational needs (Speciální pedagogické centrum) run by the Ministry of Education. Quality of educational services is very different, from very high standard to very bad approach. Social services are vaguely developed and there is very low awareness about ASD and its special needs, families have problems to obtain help they need. They are not enough parents' organizations supported by government and local authorities.

There is not any established protocol in the public health care system for the detection or early recognition of ASD. There is neither database information nor case registry described but an epidemiological study of prevalence of ASD is currently being developed in 14 Districts in the Czech Republic (Table 9).

### **Scotland**

There is a protocol for ASD early detection established by a multi-disciplinary team; Paediatric Health Services are responsible for its execution and most children are diagnosed in the Public Health System, whereas adults are usually diagnosed in the private sector. The health system has improved for children although there is still a shocking lack of understanding regarding Biological and environmental influences Psychiatry are completely failing adults, both in terms of detection and treatment. It remains a high use of anti depressant and anti psychotic drugs with little evidence of effectiveness.

The official body or institution in charge of deciding what is the most appropriate educational plan for children with SEN is the Department of Education, but can be influenced by the Health Authority. Many children placed out of area as do not have local expertise to accommodate them. Autism outreach education service is excellent, but under resourced. There is very low awareness about ASD and its special needs, families have problems to obtain help they need from social services. Regarding databases, the centre responsible for case registry is the Communication Clinic and the Department of Paediatrics. It has approximately 400 children (a mix of previously discernable cases and all new cases).

## **Denmark**

ASD is classified as a psychiatric condition. There is a protocol for ASD early detection managed by the public health care system and University of Aarhus (NANEA) but the cases are classified and reported using the ICD-10. Social services generally have a poor level of understanding of ASD. There is one main parents' organization and several others but their situation depends very much on political issues.

Regarding databases, there are two case registries: NANEA with 499 cases since 1990 and BUP database in the National Health Care System since 2005 but the number of cases registered is not provided here. They list other possible databases that might be available with ASD diagnosis information, such as the Danish National Hospital Registry and the Danish Central Psychiatric Registry.

## **Italy**

The questionnaire was focused on the Verona region. There is a protocol in the public health system for early detection of ASD with the M-CHAT but it is not described and there is no well-child surveillance protocol after 18 months. In Italy there is no specific code on autism in a disability assessment system and people with autism receive a general assessment of mental disability. Also there is no official body or institution in charge of deciding what is the most appropriate educational plan for children with SEN but there is one for issuing the disability certificate (Neuropsychiatry child and adolescent Department). The Italian parent's organization is connected and works with the public health autism centre.

This respondent reports having charts that include all clinical types of ASD data since 12 years ago with 453 cases from the Neuropsychiatry child and adolescent Department and the Public Health Autism Centre but not a real registry. There are not special schools specially meant for children with ASD in this region.

## **Spain**

A pilot project on ASD screening using the M-CHAT is being carried out in several Spanish regions order to improve awareness among primary healthcare professionals and to get some preliminary figures regarding ASD incidence in Spain. Most of the special schools are managed by parents' support groups and not all children with ASD participate in public education program but also in private education programs, private therapy, other social services (day care centres, residences, etc.) or at home.

There are two national parents' federations, several regional organizations and many different associations. All of them are autonomous and independent. Even when they belong to a federation, they all gather their own data, and the federation has none. In Spain there is no centralised data, there are different services with data (diagnosis centres, schools, early intervention programs, residential homes, etc.) and no population epidemiological study has been still carried out.

## **England**

The unique accepted standard classification of ASD in England is ICD-10 and not DSM-IV TR and there is another ASD subtype, not described in other countries, named "pathological demand avoidance". There is an early recognition protocol of ASD but not with a standardized procedure. The official body or institution in charge of deciding what is the most appropriate educational plan for children with SEN is the Local Authority Educational Department. In the education sector, there are concerns about inclusion failing complex children in many ways. Regarding Social Services there is lack of qualified staff (very low salaries are not the incentive to specialize in this direction). The

biggest condition for most financial benefits is not the poverty of a family and either not the fact that there is a disabled child in this family.

The parents' organizations started in 1962 and grew into the National Autistic Society (NAS). There are other groups on a more local level providing range of services. In England, the major study (NIASA) 2003 led to a national autism plan for children (nap-c) containing recommendations and protocols re screening and assessment. There are local ASD-PDD Registries and in different health services area, not national but there have been many epidemiological studies of ASD from 1978 in South London (Table 9). Also NAS has data collected via helpline (35000 enquires a year)

## **France**

The accepted standard definition of ASD is ICD10 and the French Classification (CFTMEA-R 2000). ASD is considered as a psychiatric disorder. It is declared that there is now a trend to make the diagnosis in a more consistent way, and to make it earlier (using standards). There is an established protocol in the public health care system for early detection of ASD with recommendations since November 2005 from the French Psychiatry Committee and High Authority of Public Health. Also it is said that diagnosis should be done by a multidisciplinary team with professionals very well trained about autism. It is highly recommended to perform an ADI-R but before 3 years, clinical assessment by a psychiatrist is considered to be more specific. It is also highly recommended to perform psychological tests as Wechsler. ADOS is not yet inside these recommendations, but it is now systematically performed in the reference centre. There are 17 reference centres on Autism diagnosis in France. There is one in the participant region (Rhône-Alpes/Isère).

The official body or institution in charge of deciding what is the most appropriate educational plan for children with SEN in the region we are dealing with is "Maison Départementale des personnes handicapées". The medical doctor in charge of the child, for example, the GP or psychiatrist, is the person who issues the disability certificate. There is a tendency to maintain ASD children in mainstream schools when possible.

Social Services are developing and they are not still enough to meet demand. There are three national parents' associations: Autisme France ([autisme.france.free.fr](http://autisme.france.free.fr)), Sésame Autisme ([www.sesame-autisme.com](http://www.sesame-autisme.com)) and Pro Aide Autisme ([www.proaidautisme.org](http://www.proaidautisme.org)). The case registries information provided is RHEOP (Register of Disabled Children and Isère county Perinatal Survey) with 181 cases of autism and 409 cases of other ASD from 1992 (registration of the child at the age of 7) and the other case registry is the Haute-Garonne county Perinatal Survey managed by INSERM (public centre) with 111 cases of autism from 1998. It is declared that it constitutes the best contact for accessing to ASD data is INSERM.

## **Malta**

In Malta, there is no universal coverage public health service. The Health Care System has no specialised facility for children with ASD and relies on the partly subsidised services of the specialised facility of the Eden Foundation.

They have a very standardized protocol of ASD Early detection and diagnosis. The child is first screened at the Eden Foundation and if ASD is suspected then the child is referred to the Structured Training and Education Programme (STEP) for children with ASD. Then a detailed assessment is carried out at the STEP centre for one hour along six weeks until the Psycho-Educational Profile Revised (PEP-R) is administered. Within these six weeks also, the child is assessed by a Psychologist using the Diagnostic Interview for Social and Communication Disorder (DISCO) and Bailey Scales of Infant Development. The child is also assessed by a speech pathologist and an occupational therapist for the child's communication development, motor coordination and self help skills respectively. At the end of these six weeks a meeting is held including all professionals and the parents/guardians where a diagnosis and individual educational plan are drawn up.

The Government Education Division has a Special Educational Needs Statement Panel which decides the most appropriate educational plan for children with SEN and has statistics on children statement as having special educational needs and who often receive extra personal support in kindergarten centres (3-4yrs). The Eden Foundation Education programme (STEP) has been running since 1995 and has since 2002 been accredited as a quality service by the accreditation service of the National Autistic Society of the UK. Children either attend 1 or 2 days a week, or afternoon sessions, or are supported in the school and community. STEP has built expertise and its reputation in Malta so that government subsidises it as a service that is otherwise not provided by the government itself. Moreover, this service is dedicated to inclusion and so most of the clients are in mainstream schools (which applies to all children with special educational needs: only 0.4 percent of the total student population attending special schools). Around 80% of students identified as having autism are in mainstream schools and classes with extra individual support. These support personnel visit the Eden Foundation facility and tutors from Eden visit the schools to ensure consistent approaches to support the children. The institution in charge of issuing a disability certificate is the Government Ministry for the Family and Social Solidarity. There are a variety of social services that can be accessed by families: one that is directed expressly at supporting the family in coping also with child rearing; and one that is expressly directed at supporting persons with disability.

About parents' organizations, there is only a self help group and does not organise services except meetings. About ASD data, the Malta Government Education Division has statistics on children statement as having special educational needs and who often receive extra personal support in kindergarten centres (3-4yrs). In health and education, there is already data that specifies diagnoses of ASD, but no access is usually given. The Child Development and Assessment Unit can furnish a list of children diagnosed as having autistic disorder (though in recent past they were often diagnosed as communication disorder). The Eden Foundation has the largest list of client with autistic spectrum disorders, but they do not include all cases.

## **Poland**

There is no protocol for ASD early detection and compulsory education starts at 6 years old. Most cases are diagnosed by private services. There are few diagnostic centres even private and to get an appointment with a good one children have to wait for a year. There are lots of cases of individual education of children with autism at home, isolated from other children. There is no official body in charge of deciding what the most appropriate educational plan is for children with SEN. This depends on the parents' decision. The "Disability assessment committees" (around 305 in Poland) are in charge of issuing the disability certificate.

There is a National Autism Association – 14 centres. There is also AUTISM-POLAND gathering around 40 organizations that deal with autism, not necessarily parents' support groups. These parents' organizations are very scattered throughout Poland and it is hard to do things together. Every organization deals with its own problems and has no time to do something beyond that on more national scale. Government agencies do not do diagnosis or treatment. Most work is done by NGOs.

Regarding databases, the SYNOPSIS Foundation is now trying to convince various influential government institutions to pass certain legislation that would introduce the separate code of autism for the disability assessment system in Poland. That would enable to track the number of people in Poland who received the disability certificate assessing autism. This could lead to the possibility to estimate the number of people with autism in Poland (even though such numbers will be too low anyway, as not all people are diagnosed with autism even if they suffer from this disability, and not all diagnosed go to assessing committees for the special certificate).

## **Bulgaria**

There is no protocol for ASD early detection; autism diagnosis is made in Health System and the health authorities do not gather data regarding ASD diagnosis. There is no case registry or

epidemiologic studies. It is the participant country with the latest age for starting compulsory education (7 years old). There is no available data regarding preschool and day-care facilities. There are no special schools for children with ASD but some may be enrolled in schools for children with moderate mental retardation and school services for SEN children are in process of development. There is no clear rule about which is the body or institution in charge of issuing the disability certificate. The first parents' organization was established recently, which has national coverage.

## **Portugal**

ASD is considered a medical (neurological) condition with behavioural, cognitive, psychological and educational repercussions. There is a clinical database at the "Centro de Desenvolvimento da Criança Hospital Pediátrico of Coimbra" in collaboration with the education services of the country. All people with ASD symptoms are referred to this hospital, This hospital is also in charge of issuing the disability certificate. There are also two parents' organizations for ASD with over 300 families registered. They have carried out a prevalence population based study.

## **Brief comments and conclusions**

Many papers published in the last decade alert us to the possibility of rising ASD prevalence but they also open the possibility to other explanations for the high observed prevalence that could be related to a true increase (Fombonne, 2005). In Europe, a few countries have shown their interest in these questions although most of the prevalence studies have been carried out in the United Kingdom. Since 2004, the EC has been conscious of this problem and finally the first European project was funded by the DG-SANCO. Among other aims, the EAIS attempts to gain consensus about a harmonized method to explore and measure the ASD prevalence in several European countries. To do that, a previous questionnaire focused on services and data access was designed and completed by 11 partners of the project. This is the first time this strategy has been used in Europe and it provides some preliminary information that improves our understanding of the challenges in conducting an ASD prevalence study in several European countries/regions.

This questionnaire (Q-EAIS) solicits details of the services provided by health, educational and social systems to people with ASD, as well as information about existing ASD parents' organizations in each country. Most of the information obtained clearly illustrated the variability of the services provided by different countries as well as some intra-country differences. At the same time, there is clarification of the most common diagnostic criteria and subtypes used in these countries, as well as information about the existence of registries and/or prevalence studies developed within each country and these are to be considered among the advantages of this questionnaire. Finally, the nature, confidentiality and accessibility of ASD data, by both public and private sectors, are investigated.

These eleven countries represent more than 250 million inhabitants, of which nearly 48 million are below 14 years old. Even though we have not yet selected the geographic areas where the prevalence study could finally be developed, the expected prevalence rates based on the published literature provide us with a crude mean figure of 288,000 children with an ASD diagnosis in these eleven countries (assuming the same prevalence rate of 6 cases per 1,000 for the whole age range). They also show different features in terms of socio-demographic characteristics and social organization that calls for the design of a harmonized prevalence study in Europe that can accommodate these differences.

A preliminary picture of how some particular countries handle ASD information may be obtained from the 'analysis by country' section besides the descriptive analysis section. The most important conclusions of this first approach are:

### About the questionnaire

1. The Q-EAIS is a new tool for obtaining a preliminary picture of the ASD services and data accessibility in different countries.
2. The Q-EAIS allows us to analyze and evaluate descriptive information in order to design an epidemiological study.
3. A second version of the Q-EAIS (Q-EAIS Modified) is being built in order to improve and facilitate an aggregated data analysis.
4. A plan for validation should be added to this new questionnaire (Q-EAIS Modified).

### About the participant countries

5. All countries, except those that are already developing a population registry, need to organize and harmonize the information on ASD services and organizations before conducting any population-based epidemiologic study, for example, a prevalence study.
6. A prevalence study could not take place in any of the countries based on only one of the services involved in ASD management because of the complexity of the diagnosis, the variability of services provided, the lack of services to meet demand, the lack of data harmonization, the differences among services regarding ASD data collection and the ethical and legal restrictions on data accessibility. Thus, a multiple-source approach to a prevalence study based on retrieving data from different service providers in each country (medical, educational, and social) will likely be needed.

### About the prevalence study design

7. A harmonized prevalence study is still viable in most of the countries explored by the Q-EAIS.
8. However, in order to carry out a prevalence study in each particular country, the levels of data access and the institutional support need to be assessed in parallel with a plan of validation of the information to be gathered.
9. A preliminary draft for a prevalence study design has already been developed. The viability of this general approach has to be tested in the next phases of this strategy.
10. A short checklist (a short list of the most important limitations for conducting a minimum prevalence study) should be designed to be filled in for those countries partners that are willing to carry out a pilot prevalence study in the whole country or in one of its regions.
11. This checklist will have to be carefully analyzed by the study responsible in close collaboration with the partner involved and a pilot study will be developed country by country in a close collaboration between the EAIS Project Leader and the team responsible for Work Package 7 of the EAIS project titled “Characteristics of ASD in Europe”.

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