ASDEU work package summary – January 2018

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Work package 1: Prevalence of autism spectrum disorder (ASD) and related social and economic costs
Task 1.1: Prevalence of individuals with an ASD by age and gender in the European Union.
Summary based on: Interim report M30, 9 November 2017
Task lead: Manuel Posada de la Paz

Objectives of Research

This three year European Union funded research commenced in February 2015. It aims to assess the varying research tools/methods for measuring prevalence of ASD (Autistic Spectrum Disorders) in the EU and how well they compare in terms of autism detection. Currently some countries are utilising information obtained by a parents' questionnaire (SCQ); whilst others are basing diagnosis on data obtained by teachers (Teacher Nomination Form, TNF.

The research is being led by Dr Posada of Spain and involves researchers from 12 countries. See Appendix 1 for the definition of ASD adopted for the various studies in this report**.** The 12 countries researched have been determined by "broad ad hoc European geographical representation".

Iceland, Finland, France (two regions) and Denmark (Appendix 2) were also selected due to significant experience in developing registries based on their whole population of children.

The other 8 countries (Appendix 3) have been selected as they are carrying out various ad hoc studies including school based screening strategies. For more information on the research undertaken by each country (Appendix 4)**.** It is hoped that the difference in socio-economic factors and the differing development of national health/social care organisations will provide information regarding European measurements of ASD prevalence i.e., "parent's versus teacher's questionnaires". A template (Appendix 5) to standardise the reporting of each research site was developed by the ASDEU programme.

Key Findings

Prevalence studies utilising data gained via school questionnaires

In Vienna, the researchers felt that the response rate was a "lower than expected" 19.3%. This was partly due to the amount of administration/paperwork that the schools had to carry out in order to meet ethical requirements. This meant that many schools felt that participating "was too much effort". Participating schools reported that parental motivation for participating in this study was low. Therefore the response rate was "significantly lower than anticipated.

This type of research accessibility issue was also experienced in Bulgaria where teacher were "overwhelmed" by their routine work and also expressed a concern with identifying issues to parents who they knew would be resistant to suggestions that there might be an issue.

These comments were echoed from the researchers of the Pisa region of Italy. The concerns respectively translated into a 44% and 45% acceptance rate by schools.
Despite teachers again feeling “overwhelmed”, Spain and Poland had a comparatively high response rate of 69% and 73% respectively. The Spanish researchers attribute this to hiring enough assistants to visit the schools in person thus “putting a face to the project”.

Romania received a 100% response rate (from 122 schools – a random sample of the total). This was attributed to the “strong links” that the researchers had with the Romanian Education ministry and the collaboration received from schools themselves. Portugal had only a 30% response rate in May 2017 despite various emails and phone calls. However, personal visits were made after May 2017 which led to an overall response rate of 87%. Ireland carried out studies in three areas with an overall response of 71.66, all those this figure was aided by Waterford City the largest research location having a response rate 86% compared to 64% and 65 % from Galway city and Cork City respectively.

Overview of registry-based sites activities

In the second part of this study, Denmark, Finland and Iceland estimated the prevalence of ASD in 7-9 year old children using nationwide registries data. Whilst France will be doing the same but with regional statistics. For these four studies the definition for ASD is ICD10 diagnosis codes: F84.0; F84.1; F84.8 and F84.9.

Iceland had a prevalence of 267.9 per 10.000. (Live births 2006-2008 with a diagnosis of ASD by 2015).

Finland had an overall ASD rate 3.4 per 1000. Based on all children born in Finland 2006-2009 and followed up by 31.12.2016.

In France there is a draft results table (currently empty) the results when calculated will be shown per 1000 of the same age residing in the same area at follow-up time.
In Denmark there was a national cohort study based upon all births during the period of 2006-2008 giving a total of 193 620 of 7-9 year olds in 2015. Unfortunately at the time of publishing this report “specific data on birth population and ASD was not available at this time”.

Other Observations

The report purported that irrespective of the causes of the increasing prevalence, it is a reality that there are now more ASD cases diagnosed during childhood and adolescence that need care, attention and treatment. Moreover, if an increasing prevalence is a reality, incidence would have been rising during previous years, and improving research into environmental causes should be incorporated into autism research policy decisions. Prevalence is also an important measurement for the burden of disease analysis and for policy-making decisions. In fact, prevalence and some other related measurements are used to define and design health, educational and social resources, but the social and economic burdens of ASD have not been adequately recorded as epidemiological indicators, except in some specific situations, the report observed.

This research is not necessarily conclusive if one was wanting to assess clear ASD prevalence data for all participating research countries. However, it provides very useful data in terms of assessing various methods being utilised throughout Europe and their appropriateness. The Appendix document (“WP1 Prevalence M30- list of annexes) has a section for each country written in that country’s own language. Dublin`s information consists of: a letter to parents, consent form, parental questionnaire, ethical approval, invitation to schools, Social Communication Questionnaire (SCQ) etc. If one is able to read any of the research participant’s languages it is worth exploring the annexes in order to get a better idea of this research and its processes.

Appendices

Appendix 1

For the purposes of this study, a case is defined as a child who fits the ASD definition of the DSM-5. However, old DSM-IV subcategories under the Pervasive Developmental Disorders codes 299.0 and 299.80 - ICD10 codes F84.0, F84.5, F84.8 and F84.9, Autism, Asperger’s Syndrome, Atypical Autism and Pervasive Development Disorder not otherwise specified respectively would be also used.

Appendix 2

The other four use standardised data belonging from either population-based registries or a national surveillance system”. Denmark, Finland and Iceland as well as two regions from France.

Appendix 3

Eight countries defined a cross-sectional study design to carry out the ASD prevalence estimation. These countries are: Italy, Spain, Portugal, Poland, Romania, Bulgaria, Austria and Ireland

Appendix 4

There were prevalence studies undertaken in the countries of: Bulgaria, Poland, Romania and Spain.

In Austria, Italy and Portugal, specific provinces or regions were picked in order to estimate the country’s prevalence e.g. in Austria it was Vienna. In Ireland a method of parental screening versus teacher nomination was utilised. Denmark and Iceland were all able to produce data on children (aged 7-9 years), in their respective countries, with ASDs. Finland offered data of children with ASD based upon results from a register based study. Finally, France produced a report of ASD prevalence by gender and age based on two registries of childhood disabilities.

Appendix 5

- Title of the study
- Study design
- Geographical, Social & Educational Setting
- Study Population
- Ethical Permissions Process
- Preparatory Study Procedures
- Case definition and inclusion criteria
- Implementation of Screening Protocol
- Description of the actions followed to carry out diagnosis evaluation
- Data management

- Main Numerical Outcomes
- Description of the actions followed for the aggregation of diagnosed ASD cases (mainstream classrooms, special units, or special schools...)
- Description of the actions followed for medical assessment /checking of phenotypic condition (when applicable).