

Autism Spectrum Disorders in the European Union – ASDEU. Summary of Report WP1. Task 1.2 Burden of ASD and Task 1.3 Cost of ASD screening.

Background

Date of report: 25.6.2018. Funded by: European Commission. Health and Consumers, Directorate-General Directorate Public Health Unit, Program Management and Diseases. WP1 Tasks 1.2 and 1.3. Lead: Martin Knapp and Pedro Serrano, LSE & BioAvance. Project Coordinator: Manuel Posada de la Paz. Project website: www.asdeu.eu

The tasks were broken down into three studies:

- 1.2.1 Health Burden: Disability-adjusted life years (DALYs)* due to autism in Europe.
- 1.2.2 Economic Burden: Economic burden of Autism Spectrum Disorders in the European Union - Cost of illness study
- 1.3 Economic impact of a screening program for ASD

Objectives of the research

The studies assessed the burden of ASD and the potential impact of ASD screening in primary care in 14 EU countries: Austria, Belgium, Bulgaria, Denmark, Finland, France, Iceland, Ireland, Italy, Poland, Portugal, Romania, Spain and the United Kingdom.

The objective of study 1.2.1 was to estimate the health burden of ASD in terms of disability-adjusted life years (DALYs) in the participating countries.

Study 1.2.2 estimated the cost-of-illness of ASD in the countries involved in the ASDEU project, using an on-line survey aimed at children and adults with ASD.

Study 1.3 was particularly developed in order to evaluate the transferability of a Spanish ASD screening programme for other participating countries in terms of the economic impact at national level.

Study 1.2.1: DALYs (Disability-adjusted life years) due to ASD

Methods

DALYs due to ASD were calculated as the sum of years of life lost (YLL) due to premature mortality in the population and years lost due to disability (YLD) for incident cases of ASD: **DALY=YLL+YLD**. The data required to estimate years lost due to disability or YLD were: disability incidence, disability duration, age of onset, and distribution by severity class, all of which had to be separated by age and sex. These required estimates of incidence, remission, case-fatality rates or relative risks, by age and sex. The population distribution by age groups were obtained from the Eurostat databases. Study 1.2.1 involved a literature review to identify population-representative studies reporting prevalence, incidence, mortality and life expectancy for ASD. The researchers estimated DALYs for two ASD categories: autistics disorder and other ASD (PDD-NOS and Asperger's syndrome and compared their estimations with the data reported by **The Institute for Health Metrics and Evaluation at the University of Washington**, which has been gathering worldwide DALY data since 1990. **Results** Total DALYs for ASD had direct relationship with country population size and ranged from 199.28 and 35,326.45, which correspond to Iceland and France respectively. A lower DALYs estimate was obtained for females than males in all countries for both ASD and other ASD conditions. By age we found that ASD generate 0.86 DALYs in the age group above 60 years and 19,917.84 DALYs in the age group of 0-4 years.

Study 1.2.2: Economic burden of ASD

Methods

To estimate economic burden in study 1.2.2, several information sources were reviewed including an analysis of the 12 ASDEU countries in and their healthcare systems and a review of use of resources related to ASD. To best estimate the cost-of-illness in many countries, a bottom-up approach was used, gathering data directly from individuals with ASD and their families using an online survey. The questionnaire for individuals with ASD and their families was anonymous and designed to collect data of use of services related to ASD (healthcare services, social services, education, housing, etc.) in the last 6 months by patients and families, and productivity losses related to the ASD. It was developed initially in English, translated into the other appropriate 11 languages and adapted in order to take into account any particular features of the healthcare and education systems for the participating countries. The questionnaire collected qualitative information to characterise the sample and quantitative information in order to estimate costs. When the services are paid directly by the person with ASD or their carers costs were requested in that individual's national currency.

Results (Please note N= sample size)

Included in this report: a) descriptive analysis of data collected from patients with complete surveys by 2nd March 2018 and were resident in one of the 12 countries surveyed (N=1667), and b) the estimation of the average cost for 6 months per patient in each country.

Spain, France and Italy (947 individuals, 58% of the whole sample), had the largest response rate. The authors alert the reader that for several reasons (see main report p.25) the "results do not represent necessarily the reality of the whole population but the reality of the people who responded to the questionnaire". 82.21% of responses were submitted by parents; 21% of the sample was 21 years old or older; 76.96% of the sample was male. The subtype of ASD was autistic disorder in 55.73% of the sample and 28.61% was Asperger's syndrome. The estimated results are the following: The direct costs per individual for 6 months go from 797 € in Romania to 11189 € in Denmark. Special education services are the costliest resources per individual, followed by the tutorial support. Other health and social services are an important part of the costs paid directly by individuals with ASD and carers. The costs of productivity losses from carers, for 6 months, go from 307.68 € per carer in Poland to 4467.41 € per carer in Austria.

Study 1.3: Economic impact of a screening programme for ASD

Methods

For the study 1.3 an exhaustive literature review of studies that estimate costs of early ASD screening was carried out. A Spanish study (Garcia-Primo 2014) served as a basis for a transferability evaluation of ASD screening programme to other countries. The hypothetical screening programme used the M-CHAT questionnaire that was applied during a well-baby check-up visit between 18 and 24 months of age. Suspicious cases were confirmed by paediatricians through a phone call and confirmed positive cases were referred immediately to a specialist. To estimate total cost of the intervention, resources necessary to carry out the intervention had to be identified, measured and valued.

The resources considered for the evaluation included:

- Time of the researcher to train paediatricians and nurses;
- Time of paediatricians and nurses to attend the training and to perform the screening;
- Telephone calls (to confirm suspicious cases);
- Printing service (questionnaires);

Costs of planning and development of the project, nor health-care centre maintenance were not included.

Results:

The results showed the cost per screened child and the total annual cost of a universal ASD screening for the fourteen countries involved in this project. Cost per screened child ranged from 1€ in Bulgaria to 13€ in Iceland, depending mostly on salaries level. The average cost per screening in the 14 countries was 6.4€. Regarding the total annual cost per country, the UK was the most expensive by far with an annual bill of 6,668,059 € followed by France and Italy with projected costs of 5,047,750€ and 3,903,753€ respectively being the size of the country the main driver of these costs.

The authors conclude that a universal ASD screening program would be feasible in Europe. Well-being child visits at 18 and/or 24 months in primary care could serve to introduce the program, which could allow to differentiate those children who are likely to be out of normal developmental limits and need further evaluation. The goal is always a prompt referral of children at high risk of ASD to specialized care.