Autism Counts
A Report on Autism Spectrum Disorder prevalence estimation in the Republic of Ireland

Executive Summary

Principal Investigators: Dr. Mary Rose Sweeney & Professor Anthony Staines

Co-investigator: Dr. Andrew Boilson

From the School of Nursing and Human Sciences, DCU

Funded by Irish Autism Action.
Background

Autism spectrum disorders (ASDs) are a group of neuro-developmental conditions characterised by impairments in social interaction and communication, as well as restricted, repetitive and stereotyped patterns of behaviour. Although there have been many studies on the epidemiology of ASDs internationally, uncertainty remains about the true prevalence of ASD globally. This is largely attributed to differences in measurement techniques which makes direct comparisons difficult.

In the last twenty years, the reported prevalence of ASDs has increased. The Centers for Disease Control (CDC) reported the prevalence of ASDs in the US as 1 in 68 (1.5%) in 2014 and ASDs has been reported to be as high as (2.6%) in South Korea. Changes in ASD prevalence rates reported may have several explanations: changes or broadening of the diagnostic criteria, differences in the methods used to study prevalence (sampling procedures, application of statistical methods), as well as an increased awareness among parents, professionals and the general public.

Determining the prevalence of ASDs is important for burden of diseases analysis and policy-making decisions. The prevalence of ASDs among school going children has not previously been explored in the Republic of Ireland.

The aim of this study was to estimate the prevalence of ASDs in a national school based population in three regions in the Republic of Ireland, using a protocol developed in Europe called the European Autism Prevalence Protocol (EPAP). The main purpose of the EPAP protocol was to facilitate a standardised approach to estimating ASD rates across Europe. Further details on the protocol are available at the URL below.


Methods

A cross sectional study design was employed.
The Setting

The Health Atlas Ireland (Health Services Executive - Health Intelligence Unit) [www.healthatlasireland.ie](http://www.healthatlasireland.ie) and Irish Department of Education national school enrolment data were used to identify National Schools in potential study regions. Using criteria laid out in the EPAP, three cities (study regions) were selected: Galway, Waterford, and Cork cities (Cork South Central). Both national and Special Education Schools were included in this study.

Questionnaires

Permission was obtained from School Principals in each of the regions to put a study pack into the school bags of all children in the correct age range, 6-11 years. This included information on the study, a consent form and the Social Communication Questionnaire (an ASD screening instrument) for completion by parents. Teachers encouraged children to return the pack completed within two weeks. Two reminder letters were sent to parents and a final reminder via the school text message system were sent to boost response rates. Table 1 shows the numbers of children attending National Schools invited to participate.

Table 1: Children enrolled in National Schools aged 6-11 years.

<table>
<thead>
<tr>
<th>Study region</th>
<th>Boys</th>
<th></th>
<th></th>
<th>Girls</th>
<th></th>
<th></th>
<th>Total</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Galway City</td>
<td>3518</td>
<td>51%</td>
<td>3353</td>
<td>49%</td>
<td>6871</td>
<td>100%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Waterford City</td>
<td>2093</td>
<td>51%</td>
<td>2971</td>
<td>49%</td>
<td>5064</td>
<td>100%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cork (South Central)</td>
<td>3322</td>
<td>43%</td>
<td>4404</td>
<td>57%</td>
<td>7726</td>
<td>100%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

With the permission of the School Principals at disadvantaged National Schools home-school liaison officers attempted to follow up the non-responders where language, literacy or social issues existed.

All children who obtained cut-off scores at or above 12 in their Social Communication Questionnaire were followed up to explore if they already had an ASD diagnosis (or other learning difficulty) or if they should be referred for multi-disciplinary assessment. The Social Communication Questionnaire was re-administered and those who’s scores remained high after re-screening were referred to Irish Autism Action (IAA) for multi-disciplinary assessments.
Data

All data was entered into an excel spreadsheet, validated, cleaned and analysed by SPSS.

Ethics

Written consent was obtained from parents of all participating children. Ethical approval was obtained from the Research Ethics Committee, in Dublin City University in accordance with the Helsinki Declaration of 1975 as revised in 1983.

Results

National Schools

The numbers of National Schools in each region invited and the numbers who agreed or refused to take part in the study is presented in Table 2.

Table 2: National Schools that agreed or refused to participate

<table>
<thead>
<tr>
<th>Study Region</th>
<th>Agreed to Participate</th>
<th>Refused to Participate</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Galway City</td>
<td>15</td>
<td>65%</td>
<td>8</td>
</tr>
<tr>
<td>Waterford City</td>
<td>18</td>
<td>86%</td>
<td>3</td>
</tr>
<tr>
<td>Cork (South Central)</td>
<td>7</td>
<td>64%</td>
<td>4</td>
</tr>
</tbody>
</table>

At National Schools across the three cities (Waterford, Cork and Galway) primary caregiver’s of 7,951 children were invited to complete the study booklet that included the Social Communication Questionnaire. Fifty four percent of these children were male (n = 4,268) and 46% were female (n = 3,683). Response rates were high with 69% (n = 5457) overall of those who were invited participating. Fifty eight children were identified through this study with a prior diagnosis on the autism spectrum, 45 males (78%) and 13 females (22%). On completion of the screening process 56 children were identified as having no prior diagnosis and requiring further assessment. Of these 31 (55%) of these children’s primary caregivers were not concerned about a
developmental difficulty, whereas 25 (45%) primary caregivers were aware of learning difficulties which had not been diagnosed by a health professional.

All 56 of these children with no prior diagnosis were invited for multi-disciplinary assessment but only 8 availed of the assessment, which were performed through Irish Autism Action. Five of these children were identified as being on the autism spectrum, 4 males and 1 female. Given that only 8 out of 56 children identified proceeded to the multi-disciplinary assessment the prevalence figures reported must be regarded as a minimal prevalence. The total number of children identified with a diagnosis of Autism Spectrum Disorder enrolled in National Schools across the three study regions was 63, giving a prevalence rate of 1.0%.

Special Education Schools

All 12 Special Education Schools agreed to participate in the study across the three cities (study regions). Of these 66% were male (n = 125) and 34% were female (n = 64). Response rates were low with only 36% of those invited participating. In total 69 children were screened, 50 (72%) were male and 19 (28%) were female. Thirty six of these children were identified as on the autism spectrum, 33 (92%) males and 3 (8%) females.

Due to the poor response rates at the Special Education Schools it is difficult to make an accurate estimation of ASD prevalence from this sample. This is a clearly a limitation of the study. The total number of children identified with a diagnosis of Autism Spectrum Disorder enrolled in Special Education Schools across the three study regions was 36, giving an estimated prevalence rate of 52% for this population.

Discussion

The process of screening and diagnosing autism spectrum disorders is complex and requires input from social, educational, medical and psychological services. In this study we report an ASD prevalence rate of 1% in National Schools and 52% in Special Education Schools across the three study regions. The findings of this study however should be regarded as a minimum prevalence rate across the three study regions combined taking into consideration the following factors:
While the overall responses rates for National Schools were high, a significant number of children identified and invited to attend multi-disciplinary assessment did not avail of the assessment or were lost to follow up.

Response rates at the Special Education Schools were low at just 36% and therefore cannot be regarded as representative of the Special Education school population.

Recommendations for future research

1. Continue to monitor ASD prevalence rates overtime in Ireland and across Europe using a standardised approach.
2. Conduct economic evaluations of the cost and benefits of ASD interventions.
3. A standardised approach for assessing and diagnosing ASDs is recommended.
4. A national register of all children diagnosed with ASD should be established.

The prevalence rates reported in this study are similar to recent estimates reported in the US and UK.

Future work
Since completion of this study the DCU study team have been collaborating on a three year programme, Autism Spectrum Disorders in Europe (ASDEU) funded by the Directorate General of Health and Consumers of the European Commission (DG-SANTE). This study will examine ASD rates across Europe, examine costs of ASD over lifetimes, examine service provision and best practice models for early detection and intervention. Details of the project are available at the following URL http://asdeu.eu/

All study materials, detailed methods and references used are available from DCU on request by contacting any of the following authors of this report.

maryrose.sweeney@dcu.ie
anthony.staines@dcu.ie
andrew.boilson@dcu.ie
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