



Background Quality Report:

The prevalence of autism (including Asperger's Syndrome) in school age children in Northern Ireland

Assessment by the author

Author:

Community Information Branch,
Information Analysis Directorate,
Department of Health Northern Ireland

Date: March 2022

Abbreviations:

C2K - Northern Ireland-wide information and communications network operated on behalf of the Education Authority

CIB – Community Information Branch

DE – Department for Education

DoH – Department of Health

HSC – Health and Social Care

IAD – Information Analysis Directorate

NISRA – Northern Ireland Statistics and Research Agency

SEN – Special Educational Needs

Summary:

This report provides information on the quality of the data used to produce the official statistics: The prevalence of autism (including Asperger’s Syndrome) in school age children in Northern Ireland. It informs users about the quality of the information upon which they may be drawing conclusions and making decisions.

The report is structured around the five quality dimensions for statistical outputs (from the [European Statistics Code of Practice, PDF \(458 KB\)](#)). The UK Statistics Authority’s [Code of Practice for Statistics](#) requires that:

Q3.3 The quality of the statistics and data, including their accuracy and reliability, coherence and comparability, and timeliness and punctuality, should be monitored and reported regularly.

Introduction

Context for the quality report.

‘The prevalence of autism (including Asperger’s Syndrome) in school age children in Northern Ireland’ publication aims to provide information on the incidence and prevalence of autism amongst children of compulsory school age. It is publically available on the Department of Health (DoH) website: [Autism statistics | Department of Health \(health-ni.gov.uk\)](#). Data from this report is used to support the development of, and to improve, Health and Social Care (HSC) services for people of all ages who are affected by autism (including Asperger’s Syndrome).

This publication, first published in 2014, was established based on the need for autism prevalence information following the [Autism Act Northern Ireland 2011](#). The information presented in this publication derives from the ‘Northern Ireland School Census’ collected by the Department of Education (DE) in Northern Ireland. This is an annual data collection based on enrolments as per the Friday of the first full week in October each year.

The data used to produce 'The prevalence of autism (including Asperger's Syndrome) in school age children in Northern Ireland' comprises of every child who was a registered pupil in a grant-aided primary, post-primary, or special school in Northern Ireland, and who attended for at least one day. The census includes details of the schools' Medical register where autism diagnosis is recorded.

The information from the 'Northern Ireland School Census' collected by the DE is subject to rigorous validations set out on the [DE website](#). Relevant validated data is received by the Community Information Branch (CIB) where it is subject to further validations and analysis. The report is published on the DoH website, and announced on the Stats Hub. DoH publicises the report through a press release, on their web site and Twitter. Furthermore, information emails are sent to contacts within the statistical and HSC community.

Each Official Statistics output produced by CIB contains key quality information in respect of the specific content of the statistical output. This information is provided in the definitions, notes to tables or notes to editors.

Relevance

The degree to which the statistical product meets user needs in both coverage and content.

Information presented in the 'The prevalence of autism (including Asperger's Syndrome) in school age children in Northern Ireland' statistical bulletin derives from the annual 'Northern Ireland School Census' data collection provided by the DE to the CIB in the DoH.

The DE provide CIB with aggregated statistical counts extracted from the School Census detailing the number of children identified with autism (including Asperger's Syndrome) by HSC Trust, multiple deprivation measure, urban/rural split, gender, and school year.

Information from this publication is used by a wide variety of users for a range of purposes. The Northern Ireland Assembly devolved administration and the DoH (statutory users) use the information to support the formulation and evaluation of children's social care policy. The data is also used to benchmark performance within and between HSC Trusts in Northern Ireland, for Ministerial Briefing, and to respond to Private Office enquiries and parliamentary/assembly questions.

Private companies may use these publications to monitor and target social care services for children, academics for research, and other government Departments and Agencies to inform cross-cutting policy and strategy development.

CIB ensures that 'The prevalence of autism (including Asperger's Syndrome) in school age children in Northern Ireland' remains relevant to users in a number of ways. Feedback received from readers help to shape the information collected and the content of these publications. In this way, the needs of user communities are continuously monitored, and acted upon when appropriate and practical.

The main stakeholder, the Department of Health's policy section, is consulted with regularly to ensure the publication is up to date and covers all relevant policy areas within the remit of the collection. Outside the Department, the Regional Autism Group ensures the requirements of statutory users are met.

Accuracy and Reliability

The proximity between an estimate and the unknown true value.

The statistical surveys used in the production of this publication are a census of the relevant cohort, and as such, coverage is inclusive of all children and young people involved.

As a census rather than a survey, no estimates are produced, and issues of sampling error and confidence intervals are not relevant.

Historically, children with autism were recorded within the special educational needs (SEN) register; however, since 2019/20 the SEN register only refers to those that require assistance with their learning. Pupils with a diagnosis of autism are now recorded on the new electronic Medical register and as such improves coverage and accuracy of the Autism population in schools ([SEN and Medical Categories - Guidance for Schools | Department of Education \(education-ni.gov.uk\)](https://www.gov.uk/guidance/sen-and-medical-categories-guidance-for-schools)). Coverage of the data is complete as all funded schools must submit a census return to avail of DE funding. As the data collected are from an administrative source and used for schools' management information purposes, there is basis to assume that it is within the school's benefit that the data supplied is as accurate and reliable as possible. The School Census captures enrolment information on a specific day i.e. the Friday of the first full week in October. Due to the nature of taking a snapshot of enrolments on a specific day, there may be some natural under or over-coverage.

The collection of data for primary, post-primary and special schools is facilitated by C2K who are responsible for the provision of ICT systems in schools. Each school submits an electronic return to the DE at an individual pupil level. When the data are returned to DE, a team of statistician's process and validate this information.

Further quality assurance checks are undertaken by statisticians in CIB on receipt of data, mainly trend analysis and comparison with statistical data from other datasets.

Previous data are revised if necessary and appropriate. All revisions are conducted in line with the 'Statement on Revisions and Errors' found in the DoH Statistics Charter.

[Official statistics and user engagement | Department of Health \(health-ni.gov.uk\)](https://www.health-ni.gov.uk/statistics)

Timeliness and Punctuality

Timeliness refers to the time gap between publication and the reference period.

Punctuality refers to the gap between planned and actual publication dates.

The statistical information used to produce this publication is submitted annually by statisticians in DE to colleagues in CIB. Delayed submissions are usually due to validation issues.

'Prevalence of Autism in School Age Children' is always published within a year of the reference period. In relation to the 2020/21 report the time lag between publication and the reference period to which the data refer was seven months.

The 'CIB Schedule of Publications', which provides twelve months advance notice of releases, is available at: [Statistical releases calendar | Department of Health \(health-ni.gov.uk\)](https://www.health-ni.gov.uk/statistics).

In the majority of cases, the target publication deadlines are met; however, in the event of a change to a pre-announced release date, the new date is announced, explained and updated regularly.

Accessibility and Clarity

Accessibility is the ease with which users are able to access the data, also reflecting the format in which the data are available and the availability of supporting information. Clarity refers to the quality and sufficiency of the metadata, illustrations and accompanying advice.

Key definitions are provided across the statistical publications.

The statistical publication is published on the DoH website and is available to download free of charge in two formats, one being fully accessible. Statistical tables are also available to download in MS Excel from the same site, suitable for further analysis.

: [Autism statistics | Department of Health \(health-ni.gov.uk\)](https://health-ni.gov.uk) .

There are numerous footnotes/caveats and annexes provided in the publication and tables covering a range of explanatory information.

The publication contains contact details for further information. Additional ad-hoc analysis is provided on request when appropriate. Dependent on the nature of such requests, these may be forwarded to DE for a response.

Coherence and Comparability

Coherence is the degree to which data that are derived from different sources or methods, but refer to the same topic, are similar. Comparability is the degree to which data can be compared over time and domain.

All data are obtained directly from schools and so guarantees coherence of the data. Historically, extraction of the autism identifier was taken from the SEN register; however, since 2019/20 this variable is extracted from a new electronic Medical register and relates to diagnostic status rather than any relevant special needs. As such, it improves coverage and accuracy of the autism population; however, this means that analyses before and after 2019/20 are not directly comparable.

There is currently no other official source of autism prevalence statistics in Northern Ireland; however, where appropriate, CIB compare this data to other sources to ensure the figures provided are reliable and robust, e.g. the [quarterly autism diagnostic and referrals statistics](#), published on the DoH website.

Trade-offs between Output Quality Components

None.

Assessment of User Needs and Perceptions

The processes for finding out about users and uses, and their views on the statistical products.

Data presented in these publications help to meet the information needs of a wide range of internal and external users.

Within DoH figures from 'Prevalence of School Age Children in Northern Ireland' are used by policy officials to monitor the delivery of social care services to children, to help assess Trust performance, for corporate monitoring, to inform and monitor related policy and to respond to parliamentary/assembly questions.

Outside government, the information is used by a number of charities and voluntary organisations as they lobby government. The statistics in these publications are also used by academic researchers interested in autism prevalence in children in Northern Ireland to inform their research.

We gain awareness of users of our data from ad hoc requests for information and from the receipt of invitations to relevant meetings, working groups and conferences.

User's needs are prioritised, taking account of the resources available.

In terms of accessibility, the use of tables, infographics, and alternative text have been considered and applied where appropriate in accordance with accessibility guidelines.

Performance, Cost and Respondent Burden

The effectiveness, efficiency and economy of the statistical output.

The DE collects a range of information from schools each year; to help minimise the burden on schools, information is collected in one exercise - the annual school census.

As the infrastructure to collect the data already exists, and schools need to generate much of this data for their own management information purposes, the annual operational cost to produce this publication is minimal year on year.

On receipt of the statistical information returns from DE, the statistics require approximately three weeks of working time for staff to produce the statistics, plus a small amount of time for senior staff oversight.

Confidentiality, Transparency and Security

The procedures and policy used to ensure sound confidentiality, security and transparent practices.

The statistical information returns are predefined MS Excel templates which collect aggregate information and therefore do not include personal information.

Data are held on a network that is only accessible to the statisticians who need access.

The DoH Statistical Charter contains a 'Statement on Confidentiality and Security.'

[Official statistics and user engagement | Department of Health \(health-ni.gov.uk\)](https://www.health-ni.gov.uk/about-us/official-statistics-and-user-engagement/)