





Background Quality Report:

Quarterly autism statistics for Northern Ireland Assessment by the author

Author:

Community Information Branch,
Information Analysis Directorate,

Department of Health Northern Ireland

Date: April 2022

Abbreviations:

CIB - Community Information Branch

IAD - Information Analysis Directorate

DoH - Department of Health

HSC - Health and Social Care

NISRA – Northern Ireland Statistics and Research Agency

Summary:

This report provides information on the quality of the data used to produce the official statistics: **Quarterly Autism statistics for 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 <u>European Statistics Code of Practice, PDF (458 KB)</u>). The UK Statistics Authority's <u>Code of Practice for Statistics</u> 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

Quarterly Autism statistics for Northern Ireland are statistical tables established due to the need for autism prevalence information following the Autism Act Northern Ireland 2011.

The quarterly autism statistics for Northern Ireland comprises two statistical bulletins. The quarterly children's autism statistics details the number and the rate of accepted referrals for children's autism assessments and number of children diagnosed with autism in each of the Health and Social Care (HSC) Trusts in Northern Ireland. The quarterly adult's autism statistics details the number of accepted referrals for adult's autism assessments and number of adults diagnosed with autism in Northern Ireland.

The statistical information used to produce these publications are submitted quarterly by each Health and Social Care HSC Trust, in an aggregated Excel format, to the HSC Board. Upon receipt, the HSC Board validates these aggregated autism information returns before sending to the Community Information Branch (CIB) within the Department of Health (DoH). Submission deadlines are agreed with the HSC Board on an annual basis. Delayed submissions are usually due to a lack of resources or validation issues.

The information received is transferred by CIB into Excel where counts are compiled and trend figures calculated. The quarterly autism statistics for Northern Ireland, children's and adults, are published on the DoH website following announcement on the Stats Hub.

Additionally, information emails are sent to contacts within the Policy team.

Data from this report are used to monitor the delivery of services for people diagnosed with autism, to help assess HSC Trust performance, corporate monitoring, to inform and monitor related policy, and to respond to parliamentary/assembly questions.

Relevance

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

The <u>Autism Act Northern Ireland 2011</u> requires HSC Trusts to provide autism prevalence information for Northern Ireland. No source for prevalence for the whole population exists ¹ and this collection of incidence of autism diagnosis is the only population wide source available.

The information presented in the quarterly autism statistics for Northern Ireland consists of aggregate tables received from the HSC Board who receive data submissions from each of the five HSC Trusts. There may be some instances of private referrals and diagnosis that are not included in the HSC Trust returns, and as such the number of incidence and referrals presented may not reflect the total numbers in Northern Ireland. However, there are currently ongoing discussions to agree how these can be included when known to HSC Trusts.

Information from the quarterly autism statistics for Northern Ireland are 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 policy relating to autism. 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 services for people diagnosed with autism, academics for research, and other government Departments and Agencies to inform cross-cutting policy and strategy development.

CIB ensures that the quarterly autism statistics for Northern Ireland remains relevant to users in a number of ways, such as, feedback received from readers to help to shape the information collected and the content of these publications. In this way, the needs of user communities are continuously monitored, and if appropriate and practical acted upon.

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 that the requirements of statutory users are met.

Accuracy and Reliability

The proximity between an estimate and the unknown true value.

Quality assurance checks are undertaken by information officers in the HSC Trusts and returns are signed off at director level before the returns are submitted to the HSC Board for

¹ The only source of prevalence relates to school aged children and is covered in the publication 'Prevalence of Autism in school aged children in Northern Ireland'.

further validations. The HSC Board then forward this data to the CIB whose statisticians examine the returns for internal consistency and unexplained changes in trends. When appropriate, explanations are sought from the HSC Board, or individual Trust, to query unusual figures or trends.

In some instances, HSC Trusts are not able to submit a complete return in time of publication. In such instances, previous quarter's figures are rolled forward and the tables suitably footnoted.

Before publication of the bulletin, it will be proof read by statisticians to ensure the consistency of figures quoted throughout the publication with the original returns.

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.

Timeliness and Punctuality

Time liness refers to the time gap between publication and the reference period. Punctuality refers to the gap between planned and actual publication dates.

The statistical data used to produce the quarterly autism statistics for Northern Ireland are submitted quarterly by HSC Trusts to the HSC Board, who in turn, forward this information to colleagues in the CIB. Delayed submissions are usually due to validation issues.

The reports are published within three months of the reference period end. In the majority of cases, the target publication deadlines are met.

The <u>DoH statistical release calendar</u> provides twelve months advance notice of releases.

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.

The statistical publications for both children's and adults quarterly autism statistics for Northern Ireland are published on the DoH website and available to download free of charge in MS Excel format: Autism statistics | Department of Health (health-ni.gov.uk).

Where possible, statisticians will include known background information to contextualise issues with data collection, such as, workforce issues, Covid-19 restrictions, or official directives.

The publications contains contact details for further information, and where appropriate, additional ad-hoc analysis may be provided on request.

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.

There is currently no other official source of autism referrals and diagnoses statistics in Northern Ireland; however, where appropriate, the CIB compare this data to other sources to ensure the figures provided are reliable and robust. For example, 'The prevalence of autism (including Asperger's Syndrome) in school age children in Northern Ireland 2021', which is published on the DoH website: Autism statistics | Department of Health (health-ni.gov.uk).

All data submitted by HSC Trusts are comparable and collated by the HSC Board for the CIB in the DoH. Comparisons can be made over time and statistics are available from quarter ending 30 June 2014 and 31 December 2017 onwards for children's and adult's statistics, respectively. CIB ensure consistent recording, coverage and timeframes of data between HSC Trust areas and with previous years/quarters figures.

Trade-offs between Output Quality Components

Trade-offs are the extent to which different aspects of quality are balanced against each other.

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 are used by policy officials to monitor the delivery of HSC services to people diagnosed with autism, 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 in this statistical publication 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 in Northern Ireland, to inform their research.

The statisticians producing the publications have a close working relationship with policy officials, the HSC Board, and the HSC Trusts. 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.

Performance, Cost and Respondent Burden

The effectiveness, efficiency and economy of the statistical output.

As the HSC Trusts are required to submit the data used for these publications to the HSC Board on a quarterly basis for management purposes, the annual operational cost to produce this publication is minimal year on year.

Once the quarterly reports have been submitted to CIB, statisticians spend around three days on each report to validate and analyse the figures to produce the publications.

Confidentiality, Transparency and Security

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

The statistical information returns received by CIB are populated MS Excel templates which collate aggregate information and are not at client level. The co-produced templates were predefined and agreed by all interested parties.

Instances of small numbers (less than five) are supressed, and care is taken so figures cannot be calculated using information from other cells or tables. Furthermore, 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)