**Estimating Autism Prevalence in Ireland: Challenges and Opportunities**

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A note on terminology

The language used to describe autism has evolved over time and continues to evolve, reflecting changes in diagnostic criteria, research perspectives, and the preferences of individuals and advocacy groups. This paper primarily uses identity-first language (e.g., ‘autistic individuals’) in recognition of its widespread preference within the autistic community.

However, when discussing historical data sources, administrative records, or research studies, terms that are now outdated or not preferred also appear in this paper. These include medicalised and deficit-based terminology, such as descriptions of autism as a disorder, illness, disease, or condition. Such terms are included only when necessary to reflect the language of the source material, with acknowledgement that they may not align with contemporary understandings of autism. Scare quotes are used in such instances (e.g., ‘disorder’). By making this distinction explicit, the aim is to ensure clarity while acknowledging the evolving nature of autism-related language and the importance of respectful, community-informed terminology.

There is more information in the NDA’s advice paper on language and terminology paper[[1]](#footnote-1) which is being updated this year specifically to add more advice in relation to autism and neurodiversity.

Executive summary

## Introduction

In August 2024 the Department of Children, Disability and Equality published the Autism Innovation Strategy. The strategy aims to address the challenges and barriers faced by autistic people in Ireland. This is to foster a more inclusive understanding and accommodations for autistic people for a more equitable and supportive public system and wider society. The strategy sets out 83 actions to be undertaken across government departments over an 18-month period. One of these actions, action 80, has been led out by the NDA. This is:

“To better understand existing data on autism in Ireland and methods of measuring the prevalence of autism, we will compile and analyse the strengths and weaknesses of existing datasets on autism in Ireland in consultation with the autistic community and in line with the actions of the National Equality Data Strategy.”

The National Equality Data Strategy has not yet been published but the NDA has some knowledge of the proposed content of this strategy and aimed to be aligned to this throughout this paper. Measuring the prevalence of autism in Ireland is needed to inform policy and service planning. However, currently there is no reliable method to estimate the prevalence of autism in Ireland. (1) To address this, action 80 aims to examine the strengths and weaknesses of existing data sources in Ireland. This is needed to support evidence-based informed decision-making on the possible methods to measure the prevalence of autism in Ireland.

This paper has been developed in response to action 80. It provides a critical analysis of the degree to which a reliable estimate of the national prevalence of autism in Ireland may be derived from existing data sources. To support this, the methods employed to measure autism prevalence internationally were examined. In tandem with this, the paper has also been informed by the views of the autistic community in Ireland. These were sought and collected from representative organisations.

## Methods

A multi-phase sequential design was adopted. For the purpose of the paper, prevalence was defined as the proportion of autistic individuals in the population at a given time. For phase one of the review, insights that may be obtained from existing national data sources in Ireland were examined. This was in the context of the strengths and weaknesses of these sources. It should be noted this section draws heavily on the 2018 publication ‘Estimating Prevalence of Autism Spectrum Disorders (ASD) in the Irish Population: A review of data sources and epidemiological studies’ from the Department of Health. (1) The data sources reviewed include the Census, National Disability Survey, the National Ability Supports System, the National Council for Special Education data, the Access and Inclusion Model data, the Department of Social Protection data on Domiciliary Care Allowance; a brief synopsis of other possible data sources is also provided. Estimates from epidemiological studies conducted in Ireland were also reviewed considering the methodological approaches adopted in these studies. The extent to which estimates for Ireland compared to those found internationally were also examined.

In phase two, the strengths and weaknesses of the differing approaches to estimating autism prevalence in the international literature is reviewed. These include population-based screening and evaluation, national surveys, registries, administrative data, census, multiple methods and systematic review and meta-analysis. In the final phase of the work, stakeholders were consulted to provide input on the paper. This feedback is provided under key thematic areas.

## Summary of findings

The summary of the findings has been presented under each phase of the study. Firstly, presenting the findings on the benefits and challenges in estimating autism prevalence from existing data sources in Ireland.

## Estimating autism prevalence in Ireland

The paper found that while each data source has benefits, they also have considerable challenges. These challenges undermine the degree to which the data sources could be used to derive a reliable estimate of the national prevalence of autism in Ireland. While each data source had its own specific challenge, collectively they stem from the methodological approaches adopted. For example, whether data was collected specifically on autism or autism data was found from a subset of questions. Other challenges included the measurement of autism. That is, if it was based on need and not a diagnosis, self-report, or the threshold for inclusion was meeting a ‘severe’ need. The response rate, sample size and frequency of data collection also undermined the ability for some data sources to provide robust estimates of autism prevalence in Ireland.

Of the data sources reviewed, the upcoming National Disability Surveyand the Irish Health Survey present an opportunity to derive national prevalence estimates. In tandem with this, the role of the National Ability Supports System (NASS) to capture more data on autism over time could also be explored. That is, notwithstanding the challenges for each of these data sources.

## Approaches to estimating autism prevalence

The second phase of the paper examined the strengths and weaknesses of differing approaches to measure the prevalence of autism in the international literature. The strengths of one approach appeared as weakness of an alternative approach. For example, population screening with active case finding or registry data derived from multiple data sources are not confined to those with an autism diagnosis or self-reported data. Therefore, they offer comprehensive population coverage. However, these approaches can be expensive. Alternatively, secondary analysis of administrative data, linkage of multiple data sources, or systematic review and meta-analysis presented a lower cost alternative to primary data collection. They also offer the potential to examine estimates over time. This would need to be balanced with the technical challenges in linking data or conducting meta-analysis. Researchers would also need to be cognisant of the quality of data in secondary data sources, gaps in data coverage and inconsistencies in definitions or diagnostic criteria regionally and over time. Of the approaches examined, a systematic, population-based approach to estimating autism prevalence (through active case-finding studies rather than reliance solely on diagnosed cases) would appear to provide good quality reference point for policymakers. It should be noted; this approach is resource intensive.

## Stakeholder views

There was strong support amongst stakeholders for the inclusion of a specific question on autism in future censuses, although the CSO have already decided that a question will not be included in the 2027 Census. Stakeholders welcomed the proposal for a new National Disability Survey. However, the infrequency of administration of this type of survey generated caution regarding its applicability in tracking prevalence trends. Multiple concerns were raised in relation to national autism registries. These centred around issues relating to privacy and autonomy, the purpose of the registry and unwelcome precedence in other jurisdictions. Stakeholders raised that any secondary analysis of administrative data must emphasise the inherent limitations of these data sources.

In addition to the methods presented, stakeholders raised additional methods. For example, the development of the Electronic Health Record and its subsequent use for secondary analysis/research was raised as an opportunity to collect data on autism.

It should also be noted that the lack of a public pathway for adult autism diagnosis was highlighted by stakeholders as a significant barrier to generating reliable prevalence data. Stakeholders also stressed that access to diagnosis must not be constrained by concerns around resource allocation. Indeed, diagnosis was described as central to identity formation, self-understanding, and affirmation. Finally, stakeholders emphasised that any approach to data collection in Ireland should be designed in such a way that allows for comparison with methods employed in other countries.

## Conclusion

The analysis found no data source nor methodological approach to measure the prevalence of autism in Ireland is ideal. Each source of data and each methodological approach comes with its own strengths which need to be balanced with the inherent weaknesses. They need to be considered in the context of their cost, sustainability, international comparability and utility for determining levels of need and subsequent service planning.

The findings from the paper suggest a multi-component approach to estimating the prevalence of autism is warranted. This would involve, in the short-term leveraging data from a number of sources. The planned National Disability Survey and the Irish Health Survey may be an appropriate mechanism by which a national prevalence estimate could be explored further. If the Irish Health Survey were to be extended to include children, it could become a very valuable means of estimating prevalence. It may also be beneficial to explore the role of the National Ability Supports System to capture more data on autism over time. In the long term, the establishment of the Health Data Access Body may provide data that would support rich insights into this area.

# Introduction

The NDA leads on action 80 of the Autism Innovation Strategy supported by the Department of Children, Disability and Equality, the Central Statistics Office (CSO) and the Health Research Board (HRB). The action states:

“To better understand existing data on autism in Ireland and methods of measuring the prevalence of autism, we will compile and analyse the strengths and weaknesses of existing datasets on autism in Ireland in consultation with the autistic community and in line with the actions of the National Equality Data Strategy.”

The National Equality Data Strategy has not yet been published but the NDA has some knowledge of the proposed content of this strategy and aimed to be aligned to this throughout this paper.

Measuring autism prevalence is important for shaping policies that address the diverse needs of autistic individuals and for fostering an inclusive society. Accurate data on autism prevalence help to ensure that resources, services, and opportunities are distributed equitably, enabling autistic individuals to fully participate in education, employment, and community life. Understanding true prevalence of autism at a population level also serves as an important benchmark for evaluating diagnostic trends, providing a means of understanding under-identification of autism in some cohorts and helping to guard against possible overidentification in others.[[2]](#footnote-2) By investing in comprehensive prevalence data, policymakers can make more informed, equitable, and sustainable decisions to ensure that the rights of autistic individuals are upheld.

There is currently no reliable method of estimating the prevalence of autism in Ireland. (1) This lack of a reliable system has led to significant data gaps. International literature demonstrates that such data gaps along with poor quality data undermines planning of health and education services. (2,3) In tandem with this, such data gaps, at times, enabled the circulation of inaccurate or stigmatising narratives around autism diagnosis. In this context, it is important to emphasise that commentary on trends of perceived increases in autism prevalence must be grounded in robust data systems and not in speculative or anecdotal assertions. Action 80 of the Autism Innovation Strategy commits to an analysis of the strengths and weaknesses of existing datasets on autism in Ireland, in order to create better understanding of the optimal methods of measuring the prevalence of autism in future. (2) This in line with the mission of the forthcoming National Equality Data Strategy, which centres around the identification of current gaps in equality data and on how best to fill those gaps. (4) In this paper, existing data sources on autism in Ireland are critically analysed for their usefulness in estimating autism prevalence and are considered in light of a) the approaches to measuring autism prevalence adopted in other jurisdictions and b) the views of the autistic community in Ireland, which were sought and collected from representative organisations.

# Defining key concepts: Incidence, prevalence, and the challenges of measuring autism prevalence

Accurately measuring the prevalence of autism in any population is a complex task that depends on the quality and scope of available data. Before examining the strengths and weaknesses of existing datasets in Ireland and the approaches to measuring autism prevalence taken in other countries, it is important to distinguish between key epidemiological concepts that underpin prevalence estimates.

**Incidence** refers to the number of new cases of autism identified within a specific time period (e.g., per year). This measure reflects the rate at which new diagnoses are made, but does not capture individuals who received a diagnosis in prior years and those who remain undiagnosed. (5) In Ireland, complete incidence data is likely difficult to capture given the high proportion of individuals accessing diagnosis through private services.

**Prevalence**, in contrast, represents the total number of autistic individuals within a population at a given time. It provides a broader view of autism within society and can be expressed as a proportion of the population (e.g., cases per 1,000 people). (5)

When estimating prevalence, a crucial distinction exists between **true prevalence**,i.e., the actual proportion of the population that meets the diagnostic criteria for autism, regardless of whether they have received a formal diagnosis, and **apparent prevalence** (diagnosed prevalence) which reflects the number of individuals who have received a formal autism diagnosis. The former can be difficult to ascertain without comprehensive screening and evaluation methods, while the latter is often based on administrative records or clinical registries. Apparent prevalence rates are influenced by factors such as diagnostic criteria, awareness, access to diagnostic services, and social and cultural attitudes toward autism. Awareness in this context includes not only public understanding, but also evolving clinical awareness informed by autistic advocates and researchers.

**Underdiagnosis** occurs when true prevalence exceeds apparent prevalence due to barriers in access to diagnostic services, lack of awareness, or misdiagnosis. High rates of underdiagnosis of autism have been found among groups such as women and girls and in ethnic minorities, including Travellers in Ireland. It is also likely that older people are also under diagnosed although there is little evidence relating to this.

**Overdiagnosis** refers to cases where individuals receive an autism diagnosis but may not strictly meet diagnostic criteria. This can theoretically occur due to increased awareness, variability in clinical judgement, or resource-related incentives leading to broader criteria application. However, there is no evidence to suggest that overdiagnosis is a significant concern in the Irish context. In relation to the possibility that overdiagnosis results from resource-based incentives, it should be noted that most services and supports for autistic people in Ireland are based on need and not simply diagnosis.

These distinctions are important when assessing different methods of collection of population data on autism, as different approaches capture different aspects of autism prevalence. The following sections evaluate existing Irish datasets in terms of their capacity to provide an accurate picture of autism prevalence in Ireland. This is followed by a critical examination of approaches taken in other jurisdictions.

# Estimating autism prevalence in Ireland

In 2018, the Department of Health published a research report entitled ‘Estimating Prevalence of Autism Spectrum Disorders (ASD) in the Irish Population: A review of data sources and epidemiological studies’. (1) That report provided a comprehensive analysis of the various data sources that could potentially be used to estimate the prevalence of autism in Ireland. Since there is no dedicated autism registry in Ireland, various administrative databases were reviewed to see if any relevant data could support estimates of autism prevalence. Additionally, a literature review was conducted to identify any epidemiological studies related to autism in Ireland over the previous two decades. The authors conclude that each data source has limitations such that they cannot lead to precise estimates of autism prevalence in Ireland. This section of this paper draws heavily on that review, providing updates to the information in that earlier report where necessary.

## National data sources

### Census of Population

The Irish Census of Population includes questions on disability, but it does not collect data on autism specifically (see Appendix 3). The census offers some insights into functional difficulties and difficulties with everyday activities that may be associated with autism, it does not ask about any difference or condition specifically. A strength of the census is its comprehensive coverage of the population. However, the data as currently collected are too broad to provide an insight on autism prevalence in Ireland. During the consultation for the 2027 Census of Population various state and civil society stakeholders proposed the addition of a question on Autism. Ultimately it was decided not to include a question, and the National Disability Survey was seen as a mechanism by which data could be collected.

### National Disability Survey

The National Disability Survey was conducted following the 2006 Census of Population, in order to provide more detailed data on the lives of people with disabilities. (6) The survey was designed to supplement the basic information on disability collected in the census and to provide richer insights into the needs, living conditions, and barriers faced by disabled people in Ireland. ‘Autism Spectrum Disorder (ASD)’ was specifically addressed in the National Disability Survey, as part of its broader focus on communication, intellectual, developmental, and learning disabilities. If a respondent indicated that they had an intellectual or learning difficulty, they were asked to indicate which of a list of ‘illnesses or diseases’ was the main cause of this difficulty, and ‘ASD’ was one of several response options. If a respondent indicated that they had a speech difficulty, they were similarly asked to indicate the main cause of the difficulty, with ‘ASD’ provided as a response option. Finally, survey respondents were asked to indicate whether they had any difficulty with interpersonal skills due to any condition, such as ‘ASD’.

The survey did not ask directly whether an individual had a diagnosis of autism. While the National Disability Survey went further than the census by asking about autism specifically under certain categories of disability, the wording of the survey questions mean that the collected data were not suitable for deriving precise estimates of autism prevalence (see Appendix 3). The data are also now dated, and prevalence rates may have changed in the intervening period. However, a new National Disability Survey to follow Census 2027 has been proposed by the Department of Children, Disability and Equality (DCDE), and a sub-group has been established to look specifically at neurodevelopmental differences including autism. An updated National Disability Survey could potentially provide up-to-date and better data on autism, which would be useful in estimating autism prevalence in Ireland. However, given the infrequency of these dedicated disability surveys, they would not be an appropriate mechanism for close monitoring of trends in prevalence over time.

### Irish Heath Survey

The Irish Heath Survey is a voluntary annual survey administered by the Central Statistics Office (CSO). A representative sample of 5,101 people aged 18 and over were interviewed for the 2024 survey. (7) New self-reported questions on autism and neurodiversity were included in the 2024 survey. The survey found 1.2% of people aged 18 years and over have been diagnosed as autistic, while a further 4.5% suspect they may be autistic but have not been diagnosed.

While the survey is annual, it has not yet been decided if questions on neurodevelopmental differences will be included from 2026 onwards. Should they be included, the survey would be a powerful source to inform autism prevalence estimates in Ireland. However, until this is decided, we cannot plan to use this data source as a mechanism for close monitoring of trends in prevalence over time. A weakness of this survey is that it does not include children.

### The National Ability Supports System

The National Ability Supports System (NASS) is a national database that records information about Health Service Executive (HSE) disability-funded services received or identified as required as a result of an intellectual disability, a developmental delay, a physical, sensory, neurological, learning, speech and/or language disability, or autism. (8) Information collected by NASS included details relating to various services, including residential services, day service, respite services, specialist supports (e.g. Occupational Therapy) and supports for daily living (e.g. Personal Assistants). NASS replaced the National Intellectual Disability Database (NIDD, established 1995) and the National Physical and Sensory Disability Database (NPSDD, established 2002) in 2019.

A strength of the NASS is that it provides detailed information on service utilisation (based on need) and demographics for autistic individuals and captures the person’s journey through services. However, being tied to service provision, the database does not contain data on autistic people who are not receiving a service funded through the HSE disability budget or have not been identified as needing a service as a result of their autism. Additionally, there have been notable gaps in coverage in NASS, particularly in relation to children. Due to delays to the rollout of the HSE’s dedicated children’s case management system (CDNT- IMS) to Children’s Disability Network Teams (CDNTs), data from CDNTs was not provided to NASS in 2023 and 2024. As a result, there was a substantial fall in children’s services reported on NASS in 2023 from 2022. Only children receiving respite, residential, home support and/or specialised support services provided outside of CDNTs are included in the most recently published NASS data. (9) Considering both of these issues, the database’s usefulness for estimating national autism prevalence is currently limited. However, it has potential particularly once the IMS is fully rolled out and integrated with NASS.

### National Council for Special Education (NCSE) data

The 2018 Department of Health review reported that the NCSE collects data on autistic students who receive resource teaching support or are in special classes and schools. In 2016, the NCSE’s policy advice on supporting students with ‘Autism Spectrum Disorder (ASD)’ noted a national prevalence rate of 1.55% on the basis of recent NCSE data. This figure of 1.55% was derived when data at the mainstream level was still available (see below). The NCSE later reported a prevalence figure of 3.3% on the basis of their data from 2022. It should be noted that this data is administrative and based on students receiving autism specific supports in schools. (10)

As of 2024, a formal process of assessment for placement in a special class or school remains, and the NCSE continues to hold data on the number of children in special schools and classes who are autistic. However, a change in how special educational resources in mainstream education are allocated in Ireland has seen special education provision ‘frontloaded’ to schools on the basis of the school’s educational profile.[[3]](#footnote-3) (11) These changes have removed the requirement for an individual student to receive a diagnosis to receive special education supports, giving schools flexibility to distribute the allocated resources as they see fit at a local level. While this move allows for resources previously used for assessment to be redeployed into provision, there is a loss of information at the level of the individual student, as not all students in receipt of additional supports are formally identified with a specific disability type, difference, or special educational need.

### Access and Inclusion Model (AIM) data

The Access and Inclusion Model (AIM) is a programme designed to support the inclusion of children with disabilities in early childhood care and education (ECCE) settings. Launched in 2016 by DCDE, AIM aims to ensure that all children, regardless of ability, can participate in and benefit from the ECCE programme. The AIM programme is administered by Pobal. Through the model, both universal (Levels 1-3) and targeted supports (Levels 4-7) are provided to create inclusive preschool environments. (12) To be eligible for targeted support, a child must be registered on the ECCE programme with a registered Early Learning and Care (ELC) setting. Applications are submitted by both the child’s parent/guardian and the preschool provider. Both the child’s parent/guardian and the preschool provider are notified of the outcome of the application by Pobal. The number of children receiving targeted supports under AIM has risen each year from 2016 to 2022 (from 1,558 in 2016 to 8,874 in 2022)[[4]](#footnote-4).

In October 2024, as part of the suite of supports offered under AIM, a set of national guidelines to support the inclusion of autistic children in early learning and care, in school-age childcare, and in childminding settings were published. (13) However, no formal diagnosis is required for a child to receive targeted support under AIM since, in many cases, children may not have received a diagnosis by the time they attend an early education and care setting: ‘This may be because their parents are unaware that their child is, for example, neurodivergent or because the process of diagnosis is not yet complete.’ (9, p.11) As such, AIM cannot provide data that can be readily used to estimate autism prevalence among young children in Ireland.

### Department of Social Protection data on Domiciliary Care Allowance (DCA)

Domiciliary Care Allowance is a monthly payment from the Department of Social Protection (DSP) to a parent who demonstrates that their child, under the age of 16, needs a greater degree of care relative to other children of similar age. Through their administration of the allowance, the Department of Social Protection collect data on children under 16 with what the Department code as ‘severe disabilities’, including autism, who require extra care. These data revealed a five-fold increase in the number of children eligible for a DCA payment with a diagnosis of ‘ASD’ in the seven-year period to 2016, which is attributed by the Department of Health to an increase in awareness of autism. (1)

Autism organisations consulted as part of this paper’s development have noted that this is often used a source of significant misinformation about autism prevalence, whereby a narrative exists that awareness of autism is driving more people to access assessment purely to access this payment. They point out that given the major barriers that exist to assessment, the high threshold to access this payment, and the high additional costs that autistic people and their families face, that this is an offensive and misguided narrative. Guidelines relating to the allowance explain that eligibility for the payment is not based on disability type, rather on the basis of the physical or mental impairment that results. (14) As such, the data are limited to ‘severe’ cases and are therefore not representative of the entire spectrum of autistic children under the age of 16. Their usefulness in estimating prevalence is therefore limited.

### Health Data Access Body

European Health Data Space (EHDS) regulations aim to progress interoperable health data exchange across EU member states. (15) This includes data for care and treatment (primary use) as well as data for research, service and policy planning (secondary use). As part of EHDS regulations, a Health Data Access Body (HDAB) will be established to provide support to access data for secondary use. A strength of the HDAB is the facilitation of linkage across several administrative, health, education, social care and survey datasets. Including primary care data, HSE disability service records and survey data. HDAB data processing introduces a range of data quality checks, resulting in better quality data when compared to individual ad-hoc data linkage or analysis from a single source of data. These checks include standardisation, deduplication, consistent coding and missing value analysis. Thus, mitigating risks associated with variation in identifiers across datasets, duplicates which can inflate estimates and variations in coding or denominators. This results in a cleaner, more reliable dataset to estimate the prevalence of autism. Therefore, once established, the Health Data Access Body may be a powerful mechanism to provide rich data in which national prevalence estimates could be explored. There is a phased approach EHDS regulations for secondary use of data, with regulations coming into force between March 2029 and March 2031. (16)

### Other data sources

For both the Department of Health review and this paper, a number of other data sources were also examined. These included data from service providers, the Hospital Inpatient Enquiry (HIPE), the HRB’s National Psychiatric Inpatient Reporting System (NPIRS), the National Self-Harm Registry, the longitudinal study on ageing (TILDA) and the Intellectual Disability Supplement to TILDA (IDS TILDA). None of the information recorded in these data sources could be used to reliably estimate autism prevalence in Ireland. (1)

Data from Ireland’s national longitudinal study of children and young people, Growing Up in Ireland study (GUI), have recently been used to estimate trends in disability prevalence over time and an increase in prevalence among young people has been reported. (17) However, GUI does not routinely collect information on autism specifically, and so this data source is currently of limited use in estimating autism prevalence. Furthermore, as noted by one autism organisation providing input to this paper, even if it were possible to attribute the increase in apparent disability prevalence seen in GUI to an increase in identified autism, this trend would need to be considered with caution. Differences in public and clinical awareness between cohorts, especially the 1998 and 2008 groups, are likely to reflect broader systemic change, including improvements in identifying autism in girls and increasing access to late diagnosis. These shifts would limit the usefulness of the data for drawing conclusions about changes in true prevalence.

### Epidemiological studies

The Department of Health review describes the findings of research studies dating from the 1990s and 2000s, which found rates of autism ranging from 4.5 per 10,000 to 33 per 10,000 among different age groups in Ireland. The considerable range in derived estimates highlight the challenges in deriving reliable estimates.

Most recently, Boilson et al. (2016) used the European Autism Prevalence Protocol (EPAP) to estimate prevalence among national school children in Ireland and reported a prevalence rate of 1-1.5%. (18) A strength of this study is that its standardised methodology facilitates comparisons to international studies. However, limitations relating to sample size and response rates (31% of primary caregivers of eligible children declined to participate in the study) mean that the estimates may not be representative of the entire population. The authors caution that their identified prevalence rate of 1% should be considered as the minimum prevalence and that the true prevalence is likely closer to 1.5%.

### International comparisons

The upper limit of the prevalence estimates in the study by Boilson and colleagues, at 1.5%, is less than half that indicated by the most recent NCSE data (3.4%). One way to attempt to validate or ‘sense check’ autism prevalence estimates in Ireland would be to examine how the results of studies in Ireland compare with estimates of autism internationally. While there have been epidemiological studies on the prevalence of autism internationally and estimates are typically in the 1-2% range, true global prevalence is unknown due to the wide variation in measurement techniques across countries that mean our ability to make direct comparisons is compromised.[[5]](#footnote-5)

Recent trends in countries such as the UK and the US suggest increasing prevalence estimates, with figures now exceeding the earlier 1-2% range. For example, a 2021 study of over 7 million children in England found 1.76% of children were on the autistic spectrum, considerably higher than previously reported. (19) Similarly, Russell and colleagues found rates of 3.1% using parent-reported data. (20) Recently the Department of Health and the Northern Ireland Statistics and Research Agency (NISRA) found the prevalence of autism for school-aged children (4-15 years) children in Northern Ireland to be 5.9% for the years 2024/25. (21) This was derived from the Northern Ireland School Census. The data used to identify students with a diagnosis of autism were from ICD10 coding in the electronic medical register.

In the USA, the Autism and Developmental Disabilities Monitoring (ADDM) Network for the Centres for Disease Control and Prevention (CDC) have found a consistent increase in prevalence estimates of autism among 8 year old children. The most recent data suggests a prevalence of 1 in 31 children (3.2%) for 2022. (22) Whereas data for 2020 suggested 1 in 36 children (2.8%) and in 2000 the estimated figure was 1 in 150 children (0.67%). (23) (24) These shifts are generally attributed to improved public and clinical awareness, (25) broader diagnostic criteria, (26) and increased access to assessment, particularly among underdiagnosed groups. (25) In this context, Ireland’s apparent trajectory is consistent with international patterns, rather than an outlier.

The quality of autism prevalence estimates varies across countries. In the following section, the main methods for estimating autism prevalence are reviewed using illustrative examples from countries that use them. Lessons for Ireland are then summarised.

# Approaches to estimating autism prevalence

There are multiple methods for estimating autism prevalence in a given population. In this section, the main approaches are discussed with reference to their strengths and limitations. Illustrative international examples have been provided.

It should be noted that attempts to estimate autism prevalence internationally have often focused on child populations, and this is the case for many of the country examples described below. More recently, however, there has been increased recognition of the need to also estimate autism prevalence among adult populations. This shift is attributable to the recognition that autism is a lifelong neurodevelopmental difference and not merely a ‘rare childhood disorder’ (as it was historically construed), an increasing rate of late diagnosis, particularly among some subgroups (such as women and ethnic minorities), and in recognition of the need to better understand autism and ageing.

It should also be noted that when a country example is given for a particular method below, this does not mean that it is the sole method employed in that country for estimating autism prevalence; often, multiple methods are used in a given country (e.g., both national surveys and administrative data have been used to estimate prevalence in the UK). An example of the use of multiple methods in a single autism prevalence study is presented towards the end of this section.

## Population-based screening and evaluation

This method involves systematically screening a broad population, typically young children, to identify those who might have autism. This approach involves using standardised tools and procedures to screen large groups, followed by in-depth evaluations for those who show signs of autism. (27) Screening can be conducted through health systems, schools, or other community services at key developmental stages.

A benefit of population-based screening is comprehensive coverage, as when implemented widely a substantial portion of the population can be reached; this helps to capture cases that may not have been identified through routine health services, especially in marginalised or underrepresented populations. Population-based screening helps with early identification, which can lead to earlier intervention. Actively screening and evaluating individuals leads to improved data accuracy and a lower risk of underreporting, since the process does not rely on self or parental reporting or medical records alone, methods which may miss cases.

While prevalence estimates based on this approach are likely to be of high accuracy, a major limitation of this approach relates to costs and resources. (27) Population-wide screening requires significant financial, personnel, and logistical resources to implement effectively, meaning it is more likely to be undertaken in a defined region or subregion than scaled up to national level. Resources that might otherwise be available to provide services and supports to autistic individuals are diverted to large-scale screening and evaluation. Another limitation relates to the fact that screening tools may produce false positives (identifying individuals as autistic who are not) and false negatives (failing to identify autistic individuals) which can result in unnecessary stress for families and in missed diagnoses. Finally, the method depends on a high rate of cooperation; estimates can be skewed depending on who agrees to participate. (27)

An example of a country in which this approach has been adopted is South Korea. In 2011, a landmark study was conducted involving a population-based screening and evaluation approach to estimating autism prevalence in school-aged children (aged 7-12 years) in a defined geographic area near Seoul. (28) First, a large cohort of children was screened using standardised tools, including parent questionnaires and teacher observations. For those flagged by the initial screening, more in-depth clinical observations were conducted to confirm diagnoses of autism. The active case-finding method was applied in both mainstream schools and special education programmes, aiming to capture both diagnosed and undiagnosed cases. The study uncovered a higher-than-expected prevalence of autism, with an estimated rate of 2.64% of the target population being autistic. (28) This was significantly higher than global estimates at the time, which were in the region of 1%. Notably, many of the newly identified cases were in mainstream schools and had not previously been diagnosed.

The South Korean study highlighted how population screening can reveal a higher prevalence of autism than previously thought, particularly by identifying individuals who may not come into contact with the healthcare system or who exhibit more subtle signs of autism. While this approach was effective in identifying undiagnosed cases, the study required significant resources and raised questions around national generalisability. Furthermore, despite identifying many more cases of autism, there were challenges in ensuring that those diagnosed could access necessary support in a timely manner.

In summary, population screening and evaluation can provide a more accurate picture of autism prevalence than other methods, but adopting this approach requires careful consideration of resources and the availability of follow-up support.

## National surveys

National surveys can be a practical and efficient method for estimating autism prevalence across large populations. By using representative sampling techniques, these surveys can provide broad, population-level data on the number of autistic people. Surveys are typically less resource-intensive than direct screening or clinical evaluations, as they can leverage existing health or demographic surveys to gather information through self-reports or parent/caregiver reports of a diagnosis. These surveys may be cross-sectional or involve a longitudinal component. Survey approaches can allow for the tracking of trends in autism prevalence over time and can provide valuable insights into how autism is distributed across demographic groups. However, national surveys are limited by their reliance on self-reported data and their typical focus on diagnosed cases, (27) likely leading to an underestimation of true autism prevalence by failing to capture all cases among communities less likely to receive a diagnosis (e.g., women and girls, communities with less access to healthcare, and those unable to pay for private assessments). Fear of stigma and the dependence of surveys on self-reported data also risk under estimating prevalence. It is also important to note that where diagnostic practices are unstandardised and vary significantly across regions, services, or clinicians, the robustness of diagnoses can be called into question, and there is also a risk of overidentification of autism in some cohorts.

Australia estimates autism prevalence through national surveys conducted by the Australian Bureau of Statistics (ABS), particularly in its Survey of Disability, Ageing, and Carers (SDAC). The SDAC collects data on the prevalence of various disabilities, including ‘autism spectrum disorder (ASD)’, through household interviews. According to the 2022 SDAC, 1.1% of Australians are reported to be autistic. (29) This represented a significant increase on previous surveys, up from a 0.8% prevalence rate in 2018 and a 0.7% rate in 2015. (30) Increased prevalence in Australia has been attributed to better awareness, diagnostic practices, and improved reporting mechanisms, similar to trends seen in other countries. (31)

In summary, surveys conducted with nationally representative samples could be a cost-effective way of estimating autism prevalence in a population. However, a major trade-off relates to the high potential for skewed estimates, resulting from sampling bias, response bias, or both. These sources of bias compromise the precision of the prevalence estimates derived from survey methods.

## Registries

An autism registry is a systematic, centralised database that collects information on individuals diagnosed as autistic. Registries typically gather data from healthcare providers, schools, and families to track autistic people across a population. Registries may include information on diagnosis, demographics, service use, and outcomes. They are often created to facilitate research, improve public health monitoring, and provide data for service planning.

Unlike national surveys or screening methods that rely on self-reporting or partial population data, such registries can provide more accurate prevalence estimates since they gather information from multiple reliable sources, including health records and diagnostic services. Registries also allow for the longitudinal tracking of autistic individuals, making it possible to observe trends in outcomes such as education and health, as well as the effectiveness of interventions over time. Autism registries are also highly valuable for research purposes, providing large, detailed datasets that can be used to study risk factors, genetic links, environmental influences, and the effectiveness of interventions. Maintaining a real-time database of autistic people, registries help policymakers and service providers to allocate resources more effectively. This includes planning for educational support, healthcare services, and community-based interventions. The 2018 Department of Health review concluded that the most reliable way to track autism in Ireland would be a ‘national disease register’ where all individuals diagnosed as autistic, using a standardised definition and diagnostic instruments, would be recorded. (1)

Limitations of this approach include that establishing and maintaining an autism registry is resource-intensive, requiring significant investment in infrastructure, data management, coordination, and continuous updating to ensure data accuracy and completeness. Collecting and storing personal data can also raise privacy concerns. (32) Ensuring proper informed and revocable consent from individuals or families, along with robust data protection measures, is crucial, and failure to do so may be a barrier to participation. Members of the autism community may be reluctant to consent to be included in such initiatives due to (understandable and potentially well-founded) mistrust in the intentions of the research and clinical communities. Finally, like several other methods, autism registries are dependent on individuals receiving a formal diagnosis. Undiagnosed individuals, especially those in marginalised communities, will not be included in the registry, potentially leading to underestimation of true prevalence. (27) It is also worthwhile noting that some types of registry, such as opt-in registries created by universities or charities have limitations in terms of estimating prevalence. While such registries can yield rich data that can be highly valuable for autism research, it can be very difficult to ascertain how much coverage of the total population is in a register of this kind or how representative the sample is of the population.

In 2013-2014 in Ireland, a nationwide consultation process conducted by The Autism and Neurodevelopmental Disorders Research Group at Trinity College Dublin, the Irish Centre for Autism and Neurodevelopmental Research (ICAN) at NUI Galway and the US-based Autism Speaks found widespread support for a national autism registry. Overall, 93% of respondents to a national survey believed that a ‘registry and biobank for autism’ is needed in Ireland. (33) Steps to creating such a registry commenced with a pilot phase in the Kildare/West Wicklow catchment area. However, progress appears to have stalled, with no recent updates available on the registry website.[[6]](#footnote-6)

One country in which registry data has been successfully used to estimate prevalence and support autism research is Sweden. Sweden’s National Patient Register (NPR), maintained by the National Board of Health and Welfare is part of a broader healthcare registry system that includes information on various conditions and differences, including autism. The purposes of the register include the monitoring of long-term health trends in the population, contributing to the development of services, and monitoring of the quality of services. (34) The registry contains information on in-patient and outpatient clinic and hospital contact. While the NPR does not include information on primary care, it is rare for a child to be diagnosed and treated only by a general practitioner and so the absence of data on primary care contacts in the registry is not considered to impact estimates of autism prevalence based on these data. (35) Several studies have estimated autism prevalence for Sweden using the registry data. (35) In one recent study, published in 2024, the prevalence of autism among 12-year-olds in Sweden was estimated at 1.1%. (36)

In summary, autism registries can be a powerful tool for tracking autism prevalence and conducting research on autism, offering rich, detailed data that can improve public policy and resource allocation. However, they require significant resources to maintain, and their effectiveness is limited by the availability of diagnoses and is dependent on the quality of reporting. In tandem with this, there is also an understandable scepticism among autistic people about registries. Thus, should a registry be considered co-designed approaches should be adopted to ensure that they are fit for purpose. This consideration would need to be balanced with the potential for the Health Data Access Body to provide the equivalent data that a registry may provide.

## Administrative data

Administrative data refers to information collected through the regular functioning of government agencies or services, such as education or social welfare systems. These data are often compiled for operational purposes but can be repurposed to estimate autism prevalence by identifying individuals who have been diagnosed as autistic or who receive services related to their autism. Unlike registries, which are often specifically designed to track autistic individuals or individuals with other conditions, administrative data is gathered as part of broader government operations and not solely for research or public health monitoring. Administrative data may include educational records relating to special education supports for autistic children, electronic medical records that show autism diagnoses, or social services data on individuals receiving disability benefits due to being autistic.

A strength of this approach to estimating autism prevalence is that it is cost effective; the data are already being collected as part of normal government operations and so the significant additional resources that would be required to create and maintain a registry or conduct large-scale surveys are not necessary. (27) Further, administrative data often cover substantial portions of the population, since they are tied to routine services like education, healthcare, and social welfare. This means that they can capture a wide range of individuals, including those who may not participate in voluntary surveys or be included in registries. Administrative systems often collect data over lengthy periods, making it possible to track individuals’ interactions with various services over time. This can be useful for studying life outcomes of autistic people. Finally, because administrative data can come from multiple sectors, they allow for a more holistic view of the challenges and support systems that autistic individuals encounter, revealing patterns across different services.

Limitations of this approach include that administrative data are not collected for the purpose of monitoring autism prevalence, so there may be inconsistencies in how autism diagnoses are recorded across different agencies or regions and over time (for example, as differing diagnostic criteria are applied). Like many other methods, administrative data only capture individuals who have received a formal diagnosis, and undiagnosed individuals will not appear in the data (unless in some cases there is a waiting list for autism diagnostic assessment). There is also service-related bias in administrative data sources. Administrative data reflect those who interact with public services, potentially underestimating prevalence among those with limited interaction with public services because they are not aware of their need or not aware of the service, individuals who receive private services outside of the public system, and individuals who do not require services at a particular point in time. Finally, using administrative data for estimating autism prevalence requires navigating complex privacy regulations and data-sharing agreements.

Administrative data have been used to estimate autism prevalence and trends over time in the United Kingdom. These include data drawn from routinely collected healthcare records (37) (38) and educational data from the Annual Schools Census. (39) (19) For example, one study using primary care data showed a 787% increase in recorded incidence of autism (new diagnoses) between 1998 and 2018. (40) The authors conclude that this could be attributable to a growth in prevalence or, more likely, to increased reporting and application of diagnosis. They argue that growing rates of diagnosis among adults, females, and individuals with lower support needs suggest that better recognition of autism in these groups has contributed to the increases.

One study using educational data showed an increase in the proportion of children identified as autistic from 0.97% in 2010/11 to 2.28% in 2018/19 across the UK as a whole, an increase of 154%. (39) The author suggests that increased recognition of autism among girls, improved awareness and identification methods, and changes to assessment practices (shifting from formal statutory process to assessments conducted internally in schools) may have contributed to the rise in the identification of autistic pupils in the UK. To derive these estimates, the authors combined a) the numbers of students with an education, health and care plan that included a diagnostic code for autism (i.e., where a clinical diagnosis has been made) with b) the numbers of students receiving autism-specific additional supports after local, school-based determination of need. It is not possible to estimate how many of the students in the latter category would actually receive a clinical diagnosis if assessed.

In summary, administrative data can be a valuable and cost-effective tool for estimating autism prevalence and for understanding service use, drawing on existing government records. They provide real-word insights into how autistic individuals interact with public systems, but have limitations related to data consistency, privacy, and the exclusion of undiagnosed individuals and those not availing of services.

## Systematic record review

Systematic record review involves analysing existing health, education, or service records to identify autistic individuals. It is a subset of administrative data but links data together from different datasets. Strengths of this systematic record review approach include that it is population-based, meaning that an attempt is made to identify all autistic children from the entire population of children in a particular geographic area. The comprehensive, multi-source approach ensures robust data. Regular updates and wide geographic coverage allow for examination of trends in prevalence, including for particular subgroups (such as gender or racial/ethnic groups). The method also involves utilisation of existing data rather than conducting new population surveys or clinical assessments. Limitations include that while the approach has been described as ‘relatively low cost’, it can be challenging to link children across multiple data sources. (27) In tandem with this, such linkage needs to be completed in line with all data protection regulations. The quality of the prevalence estimates is dependent on the quality and completeness of local records; variations in record-keeping across regions can affect data consistency.

The United States uses the Autism and Developmental Disabilities Monitoring (ADDM) Network, which tracks autism prevalence (as well as prevalence of cerebral palsy and other development disabilities) through data collected from health service, and educational records of children in targeted age groups. Started in 2000 and overseen by the US Centres for Disease Control and Prevention (CDC), among the goals of the ADDM Network is to obtain as complete a count as possible of the number autistic children aged four (since 2010) and eight across ADDM Network areas and to identify changes in that count over time. This method leverages multiple sources, including clinical diagnoses, special education classifications, and administrative data, tracking more than 220,000 four-year-olds and more than 220,000 eight-year-olds. (27)

ADDM Network sites estimate the number of autistic children within their respective area using a record review method to find children who have received an ASD diagnosis, an autism special educational classification, or an ASD International Classification of Diseases (ICD) code from a community health, education provider, or other service provider. (41) Census figures are used to provide the denominator (total number of children of that age in the target area) to derive prevalence estimates. Additional information is collected on demographic characteristics and other important conditions or disabilities, such as co-occurring intellectual disability. All sites use a common protocol for record review and abstraction. The latest prevalence estimates are that 1 in 36 eight-year-olds (2.8%) were identified as autistic in 2020. (41) However, the approach only includes children who have had contact with healthcare or education systems and about whom observations about developmental difference have been well documented.

In summary, while a systematic record review can be a relatively cost effective and scalable approach to estimating autism prevalence, its accuracy heavily depends on the completeness, consistency, and accessibility of existing records, which may lead to under-identification, including disproportionate under identification among certain population groups. It could also lead to over-identification if there is lack of standardisation in criteria applied.

## Census of Population

National population censuses can provide an opportunity to collect large-scale data on autism prevalence. Conducted at regular intervals, censuses aim to capture demographic information about an entire population. When autism-related questions are included, they offer insights into the number of individuals identified as autistic within households and communities. One of the main advantages of census data is their universal coverage, which helps overcome some of the selection biases inherent in other data sources. Unlike administrative records which may be tied to service utilisation or survey data which may suffer from limited response rates, a national census can provide a broad picture of autism prevalence across different age groups, socioeconomic backgrounds, and geographic regions. Like survey methods, however, census data on autism depend on self-reporting or parental reporting, which may be influenced by awareness levels, diagnostic availability, or social stigma. Additionally, in many jurisdictions, censuses are conducted just once each decade, limiting their usefulness for tracking changes in autism prevalence over time.[[7]](#footnote-7)

Many countries may choose not to include autism questions in their national censuses for reasons such as competing priorities and methodological concerns. Census questionnaires must remain concise to ensure high response rates, meaning only limited information on functioning and disability can be collected. Additionally, autism identification is complex and can be difficult to capture accurately through self-reported census questions.

A notable exception is in Scotland, where questions about autism were included in the 2011 Census of Population. The census questionnaire allowed individuals or their household members to report whether they had been diagnosed with a ‘Developmental disorder (for example, Autistic Spectrum Disorder or Asperger’s Syndrome)’.[[8]](#footnote-8) In total, there were 31,712 people (24,490 males and 7,222 females) ‘known to have autism’ as a result of Scotland’s 2011 Census, which was 0.6% of Scotland's population at the time. Among children aged 0-15 years, 17,348 were reported to have autism, which was 1.9% of children in this age range which is in line with prevalence estimates from other sources. The proportion of the population known to have autism decreased progressively in each older age cohort, which was attributed to significant improvements in diagnostic services in Scotland over recent decades. (42) However, the inclusion of autism-related questions in the census was short-lived, and the next census (in 2022) did not collect this information, reducing the potential for long-term trend analysis. This change was a result of ‘Question development for Scotland’s Census 2022 [which] included focus on improvements to the long term health conditions question and its response options to aid respondent understanding.’[[9]](#footnote-9)

In summary, a census offers opportunities for the collection of full population information on autism. However, due to competing informational priorities and the complexity of validly assessing autism through self-report questionnaire methods, this method has been used by countries to estimate autism prevalence only very rarely.

## Using multiple methods to estimate autism prevalence

Estimating the prevalence of autism is a complex task requiring reliable data collection methods. While individual approaches as described above can offer valuable insights, each has inherent limitations. To obtain a more comprehensive and accurate picture, researchers have employed multiple methods to estimating autism prevalence within a single study. This approach allows for cross-validation of findings and helps to identify discrepancies arising from differences in diagnostic criteria, healthcare access, and reporting practices. By integrating data from diverse sources, researchers can assess both the actual occurrence of autism-related traits in the population and the extent to which these traits are formally recognised in healthcare or educational systems.

One example of this multi-method approach is a study conducted in Sweden by Lundström et al., published in 2015, which examined the prevalence of autism in Sweden over a ten-year period. (43) The researchers used two primary methods. First, they assessed the autism symptom phenotype in a cohort of 19,993 twins born between 1993 and 2022, using a validated parental telephone interview known as the ‘Autism-Tics, ADHD, and other Comorbidities inventory’. This allowed for the identification of children exhibiting ‘symptoms’ of autism, regardless of whether they had a formal diagnosis. The study also analysed data from the Swedish National Patient Register which, as mentioned above, contains records of clinically diagnosed autism cases. This enabled the researchers to track the annual prevalence of autism diagnoses within the national healthcare system. The findings revealed that the prevalence of the autism symptom phenotype remained stable over the ten-year period, while the prevalence of registered autism diagnoses increased significantly. This suggests that administrative factors, such as changes in diagnostic practices or increased awareness may have contributed to the rise in reported autism cases, rather than an actual increase in autism in the population.

Another example of where drawing on multiple methods could potentially be useful would be in the linking of administrative data with, for example, Census data. This would allow for the collation of more comprehensive information about autistic individuals. While there would be data protection considerations and practical issues to consider with data linking of this kind, such an approach would be in line with the ‘Collect once, use often’ principle of the forthcoming National Equality Data Strategy.

## Systematic Review and Meta-Analysis

Systematic reviews and meta-analyses are an alternative formidable tool to estimate the prevalence of autism. They involve statistically synthesising findings from numerous individual studies to derived pooled prevalence estimates. They offer several advantages over individual studies.

Firstly, they increase the precision and reduce the bias in derived estimates. As data from a number of studies are combined and analysed, sample sizes are considerably greater than would be possible from one study alone. This offers greater statistical power. It is therefore possible to derive more precise prevalence estimates with narrower confidence intervals. In tandem with this, as data is aggregated across publications, it reduces the impact of random measurement errors which individual studies are at greater risk of. By drawing on data from a number of studies, the pooled prevalence estimates are likely to be more generalizable than one study alone. Given this, we can have greater confidence in the reliability of the prevalence estimates, derived from systematic reviews and meta-analysis.

They also allow a comprehensive overview of findings. As studies are combined from a number of regions, over time periods, with methodological differences, there is the potential to examine a broader scope of factors that may impact that prevalence estimates. For example, depending on data availability, it is possible to conduct sub-group analyses to examine how prevalence differs by region, time period, age group, gender, diagnostic criteria or study methodology. A considerable advantage of systematic reviews and meta-analyses is the identification of gaps in the literature where more research is needed. For example, underrepresented populations or age groups. Finally, as data is collected from published studies, they offer a more cost-effective alternative to the primary data collection required for large-scale prevalence studies.

That said, there are potential limitations to systematic reviews and meta-analyses that should be considered. Firstly, researchers need to be cognisant of the quality of the studies included in the meta-analysis. Poorly designed or methodological flawed studies would undermine the reliability of any pooled estimate. Also, studies used in the analysis may differ in their methodological approach (differing case ascertainment approaches, differing diagnostic criteria or sampling techniques). Where it is not possible to examine the impact of these differences through sub-group analysis or meta-regression, it may be inappropriate to pool estimates with high levels of heterogeneity. These types of studies are also time-consuming requiring specialised expertise. If there are too few studies to allow for sub-group analysis given the complexity of establishing a prevalence estimate for autism, it may not be feasible to conduct a systematic reviews and meta-analysis, especially one that could allow for meaningful results.

Thus, systematic reviews and meta-analyses offer significant advantages in terms of precision, reduction in bias and cost-effectiveness. However, their benefit depends on the availability and quality of published literature for the analysis and the application of strong methodological steps to address heterogeneity and potential biases in pooled estimates.

Some of the most influential systematic reviews and meta-analysis examining prevalence estimates for autism are discussed below. One of the earliest comprehensive overviews of the prevalence autism was provided by Elsabbagh et al.,. (44) Data from 36 studies were analysed to derive a median prevalence estimate of 0.17%. These studies came from across a wide geographical base, including Europe, America, Western Pacific, South East Asia, Eastern Mediterranean and Africa. The review acknowledged that the lack of data, particularly in low-income countries, undermined the power to detect differences by geographic region or socio-economic factors.

The Elsabbagh review was updated in 2022 by examining data published since 2012. (45) This incorporated estimates from 71 studies across 34 countries. It demonstrates the increase in apparent prevalence, with median prevalence estimated to be 1%, ranging from 0.01%-4.36%. Importantly, the review also examined how this increase may be attributed to factors such as changes in diagnostic approaches, socio-demographic factors and public and professional awareness.

A frequently cited review is that from Williams et al.,. (46) It examined data from forty papers to quantitatively explore the influence of study methodology and population characteristics on autism prevalence estimates. The authors employed meta-regression to examine the extent to which study characteristics explain the degree of variance in prevalence estimates. They found over half of the variation among prevalence estimates could be explained by the age children were screened, the diagnostic criteria applied, and the country studies were conducted in. Thus, the study demonstrates the methodological challenges to be considered when synthesising prevalence estimates. These methodological challenges also apply to estimates from single studies, thus this ought to be considered when reviewing stand-alone studies.

A more recent systematic review and meta-analysis was published in 2023 by Salari et al.,. (47) It examined data from a considerable number of studies (n=74), providing a sample of over 30 million participants. The estimate found for the global prevalence of autism spectrum disorder was 0.6% (95% confidence intervals: 0.4-1%). Subgroup analysis suggested prevalence estimates vary by region. For example, estimates derived for Europe (0.5%; 95% confidence intervals: 0.2-1%) were considerably different to those for Australia (1.7%; 95% confidence intervals: 0.5-6.1%). A meta-regression found prevalence estimates decreased with increasing sample sizes. As with the findings from the Williams et al., review, the impact of sample size on derived prevalence estimates is also an important aspect to consider when examining prevalence estimates from single stand-alone studies.

# View of autism stakeholders

Between March and May 2025, feedback on this draft paper was invited from organisations representing autistic people. The views received reflect both shared priorities and unique concerns in the sector. Stakeholder feedback has been grouped under key thematic areas.

## The value of reliable prevalence data

Stakeholders emphasised that the absence of reliable autism prevalence data in Ireland has hindered effective service planning, rights realisation, and public understanding of autism. Accurate prevalence data were seen as crucial for:

* Understanding the full diversity of the autistic population;
* Enabling evidence-informed service planning across education, health, employment, accommodation, and social care;
* Identifying geographic and demographic service gaps;
* Supporting forward-looking planning that reflects the needs of autistic people across the lifespan;
* Challenging inaccurate or stigmatising narratives around autism diagnosis or service use.

Feedback also highlighted the need for disaggregated data to understand how experiences of autism may differ based on intersecting characteristics such as ethnicity, gender, and socio-economic background.

## Preferred and non-preferred methods of estimating prevalence

While stakeholders argued that a variety of methods is likely needed to accurately estimate prevalence, some strong preferences and concerns were expressed in relation to particular methods.

### Use of the Census of Population

There was strong support for the inclusion of a specific question on autism in future censuses, beginning with Census 2027. Stakeholders emphasised that current census questions fail to adequately capture the autistic population, rendering many autistic people statistically ‘invisible’. Stakeholders emphasised the importance of carefully designing the question to be inclusive and understandable. It was suggested that questions in relation to diagnosis should also be incorporated in the Census, asking whether an individual has received a formal diagnosis (publicly or privately), if they are waiting on a diagnosis, and the length of time that they have been waiting. As referred to above, during the consultation for the 2027 Census of Population, various state and civil society stakeholders proposed the addition of a question on Autism. Ultimately it was decided not to include a question and the National Disability Survey was seen as a mechanism by which data could be collected.

### Use of the National Disability Survey

While stakeholders generally welcomed the proposal for a new National Disability Survey following Census 2027, concerns were raised about accessibility (particularly respondents having to complete two complex questionnaire forms in relatively quick succession) and the usefulness of this method for tracking prevalence trends, given the infrequency of administration of this type of survey.

### Use of registries

Stakeholders raised multiple, serious concerns about the potential establishment of an autism registry in Ireland:

* **Privacy and autonomy**: There is deep unease about the storage and use of personal information on autistic individuals without explicit, informed, and revocable consent. Past incidents involving the sharing of sensitive data without permission have created mistrust in state-led data initiatives.
* **Purpose and framing**: Stakeholders warned of the risk of registries being framed in deficit-based or pathologising terms, particularly when linked with issues such as labour market productivity.
* **Precedent from other jurisdictions**: Reference was made to recent debates in other countries, namely the United States, where proposals regarding autism registries have been associated with surveillance and narrow policy aims. Stakeholders cautioned strongly against replicating such approaches in Ireland.

## Use of administrative data

Stakeholders pointed to what they described as significant shortcomings in administrative data in Ireland and argued that this has contributed to poor national planning, particularly in the area of the provision of autism class placements for children. There is a concern that this shortcoming has also led to a narrative of sudden increases in prevalence within specific cohorts of autistic people, such as school children, when in fact poor data collection may be a contributing factor. It was argued strongly that when administrative data on autism are published that there should be greater transparency by government agencies with respect to the sources of the data and their limitations.

### Additional methods

In addition to the methodologies reviewed in this paper, stakeholders proposed some additional approaches and enhancements to existing systems that could support more accurate and inclusive estimation of autism prevalence in Ireland.

* Stakeholders identified the development of an Electronic Health Record by the HSE as an ‘ideal opportunity’ to collect data on autism.
* It was suggested that improvements to NASS, such as compelling all service providers to complete and submit returns in relation to service users would lead to a more comprehensive and useful database.

## Additional themes and considerations

Stakeholders raised a number of additional issues as essential to interpreting and applying prevalence data ethically.

### Assessment access and adult diagnosis

Stakeholders highlighted the lack of a public pathway for adult autism diagnosis as a significant barrier to generating reliable prevalence data. Adults without the financial means to access private assessment remain excluded from diagnostic recognition and, consequently, from prevalence estimates.

### Tension between diagnosis and service availability

Stakeholders highlighted the South Korean population screening study as an example of how active case finding can reveal significant underdiagnosis, but that the study also illustrates a broader tension: when prevalence rises, state responses may focus on managing service demand rather than upholding individuals’ rights to diagnosis and support. Stakeholders stressed that access to diagnosis must not be constrained by concerns around resource allocation. Instead, systems should be designed to scale responsively to meet need, rather than to suppress it.

### Value of diagnosis

Diagnosis was described as central not only to accessing services, but to identity formation, self-understanding, and affirmation. Stakeholders rejected the suggestion that diagnoses are frequently pursued for reasons of resource allocation, noting that most supports are granted on a needs basis and are difficult to access even with a formal diagnosis. The impact of late diagnosis on individuals and past trends of inappropriate diagnoses in the absence of access to autism assessment were also highlighted.

### Intersectionality and dual diagnosis

Stakeholders emphasised the importance of placing greater attention to the impact of dual diagnoses (e.g., autism with ADHD or intellectual disability) on individuals and to the experiences of intersectional minorities who may experience additional diagnostic and support barriers.

### International comparability

Stakeholders emphasised that any approach to data collection in Ireland should be designed in such a way that allows for comparison with methods employed in other countries. This would enable benchmarking and cross-jurisdictional learning that could improve policy development, service provision and, ultimately, help to ensure that the rights of autistic people in Ireland are realised.

In tandem with this, stakeholders also noted the influence of the changes to the diagnostic criteria for autism in the Diagnostics and Statistical Manual of Mental Disorders (DSM). For example, the shift from DSM-IV to DSM-5, which involved a consolidation of diagnosis, shifted symptom domains and included sensory issues. The general expectation internationally was that following the changes in DSM-5, prevalence rates may decrease given the consolidation of diagnosis. However, reported prevalence have increased over the period. This appears to be attributable to a combination of factors as described above. This includes, greater public and professional understanding, alterations in screening and diagnostic practices, along with broader conceptualisation and societal understanding of autism. It should also be noted, for a diagnosis to be formally recognised in Ireland, it must be recorded using the International Classification of Diseases, Version 11 (ICD-11) criteria.(48) (49)

# Conclusion

To date, there is no single reliable data source that allows for reliable estimates of autism prevalence in Ireland. There are multiple approaches that can be taken to estimating the prevalence of autism at a national level, and each has its advantages and disadvantages.

Understanding the true prevalence of autism at a population level is not only essential for identifying unmet needs and improving access to services, but also serves as a critical benchmark for evaluating diagnostic trends. Because autism is diagnosed based on behavioural observation rather than biomarkers, its identification is inherently influenced by cultural, social, and systemic factors. This introduces the possibility that changes in prevalence rates may not always reflect shifts in underlying symptomatology but rather external influences on diagnostic practice. Several factors can contribute to fluctuations in apparent prevalence beyond true prevalence. For instance, there may be a perception that access to support and resources can be contingent upon receiving an autism diagnosis. However, as referred to above, most services and supports for autistic people in Ireland are based on need and not simply diagnosis.

As public awareness increases and autism-related stigma decreases relative to other diagnoses, individuals may be more likely to pursue an autism assessment, sometimes with strong self-identification prior to formal evaluation. While these shifts can help to address historical under-diagnosis in some cohorts, they also highlight the need for careful oversight to prevent the proliferation of inaccurate diagnoses. If diagnostic thresholds are applied inconsistently this can have a multitude of sub-optimal implications. For example, lack of standardisation can result in regional differences in prevalence estimates which can undermine the reliability of national estimates. If these thresholds are interpreted too broadly, there is a risk that the meaning of an autism diagnosis could be undermined, potentially affecting public perceptions and resource allocation. It is important that robust national guidelines on diagnostic practice for autism assessment are developed. These guidelines should include the levels of support an individual requires as presented in the DSM-5. (50) The guidelines should also be applied consistently. This would support clinical decision-making across public and private settings, as is standard in several other jurisdictions. The absence of such guidance in Ireland, particularly in the context of an unregulated psychology profession and widespread reliance on private diagnostic services, contributes to inconsistencies and challenges in prevalence estimation.

At a policy level, distinguishing true prevalence from apparent prevalence allows for more informed, equitable, and sustainable decisions to ensure the rights of autistic individuals are upheld.

The findings from the paper suggest a multi-component approach to estimating the prevalence of autism is warranted. This would involve, in the short-term, leveraging data from a number of sources. The upcoming National Disability Survey[[10]](#footnote-10) and the Irish Health Survey may be an appropriate mechanism by which a national prevalence estimate may be explored further. If the Irish Health Survey were to be extended to include children, it could become a very valuable means of estimating prevalence. In tandem with this, the role of the National Ability Supports System (NASS) to capture more data on autism over time could also be explored. The NASS includes people already receiving specialist disability services and therefore is capturing ongoing service provision and unmet need for those already in services. However, a NASS based system would exclude those whose needs require mainstream rather than specialist support and those who have not yet been identified as needing support. There is an argument that if someone has not been diagnosed or are not receiving services then they are managing fine. However, this may not always be the case, and difficulties may manifest at different stages e.g. at transition points or during adolescence. For example, transitions into and through post-primary education and further education, where supports may diminish. There would be a gap therefore in providing early intervention to this cohort if NASS were the only mechanism used.

While a systematic, population-based approach to estimating autism prevalence (through active case-finding studies rather than reliance solely on diagnosed cases) would provide an essential reference point for policymakers, this is a very resource intensive approach. Given that it would likely take away resources currently being used to provide assessments and supports in a context of long waiting lists it is unlikely to be a palatable option in Ireland.

The Department of Health in their paper estimating the prevalence of autism pointed to the pragmatic approach taken by the Department of Education based on the number of children with a diagnosis of autism who are currently accessing special education services. They highlighted however, the particular lack of data on the prevalence of autism in adults and subsequent unmet needs. Once the Health Data Access Body is established in Ireland, the linkage of data from multiple sources facilitated by this body will provide a means to support secondary data analysis for rich insights into this area.

Recommendations

To support evidence-based policy and planning going forward, some recommendations derived from the analysis have been provided below. These have been separated into those which may be addressed in the short-term and those which would involve a more medium to longer-term approach.

|  |  |
| --- | --- |
| **Recommendation**  | **Responsibility** |
| **Short-term** |
| We would welcome the exploration of co-designed autism specific questions as part of the upcoming National Disability Survey. | Department of Children, Disability and Equality |
| The Central Statistics Office might consider the inclusion of autism specific questions in the annual data collection for the Irish Health Survey.  | Central Statistics Office |
| The Department of Health might consider exploring the inclusion of autism specific data fields in the Electronic Health Record  | Department of Health |
| We would welcome the integration of the Children’s Disability Network Teams (CDNTs) data into the National Ability Supports System (NASS). | Health Service Executive and the Health Research Board |
| **Medium to longer-term** |
| The National Disability Authority would welcome collaboration with the Health Data Access Body, once established, to explore multi-source data linkage in this area. | National Disability Authority and Health Data Access Body |

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# Appendix 1: Data Sources Summary

National Data Sources

| **Data Source** | **Coverage** | **Frequency** | **Autism Diagnosis Captured** | **Strengths** | **Weaknesses** |
| --- | --- | --- | --- | --- | --- |
| **Census** | National coverage | Every 5 years | No autism specific questions | Full population coverage | Long interval between censuses, specific autism question(s) not captured |
| **National Disability Survey (NDS)** | National Coverage (sample of the population who reported having a disability in census). | Infrequent | NDS 2006 captured autism indirectly. NDS 2027 will capture autism data | NDS 2027 will provide up-to-date data to measure national prevalence.  | Due to infrequent data collect, not suitable for trend analysis |
| **Irish Health Survey** | National coverage | Annual | Captures both diagnosed and captures autism suspected but not diagnosed.  | National coverage. Captures both diagnosed and suspected autism.  | Inclusion of autism questions from 2026 onwards not yet confirmed.  |
| **National Ability Supports System (NASS)** | People receiving or identified as requiring specialised disability service funded through the HSE's disability budget. | Annual | Diagnoses captured | Captures individual based data on service use and service needs. | Does not capture disability services funded outside of the HSE disability budget. Does not capture those yet to be identified as needing a service.  |
| **NCSE** | Autistic students in special classes and schools. | Annual | Diagnoses captured | Administrative data routinely collected.  | Autism prevalence based on diagnosis specific to students in special class or schools. Not all students in mainstream education in receipt of additional supports are formally identified with a specific disability type.  |
| **AIM** | Children with disabilities in Early Childhood Care and Education | Annual | Suspected, formal diagnosis not required.  | Administrative data routinely collected.  | As formal diagnosis is not required, AIM data not suitable to estimate autism prevalence among young children.  |
| **DCA** | Children under the age of 16 receiving a greater degree of care relative to other children of similar age.  | Annual | Autism captured indirectly, no specific autism question.  | Administrative data routinely collected.  | Data are not representative of entire spectrum of autistic children under the age of 16. Thus, not suitable to estimate autism prevalence among children under 16.  |

# Appendix 2: Methods Summary

Methods to estimate Autism

| **Method** | **Strengths** | **Weaknesses** |
| --- | --- | --- |
| **Population based screening** | Comprehensive coverage, captures cases that may not have been identified through routine health services. | Significant financial, personnel, and logistical resources. Where there are false positives or false negatives, this can result in unnecessary stress for families and missed diagnoses. |
| **National Surveys** | Population-level data, less resource-intensive than direct screening, allows for the examination trends over time.  | Reliance on self-reports or parent/caregiver reports of a diagnosis. Variation in diagnostic practices can undermine the reliability of estimates.  |
| **Registries** | Systematic, data derived from multiple sources (health records and diagnostic services), thus not reliant on self-report. Routine data collection supports analysis of trends.  | Requires significant investment in infrastructure, data management, coordination, and continuous data processing to ensure data accuracy and completeness. Also raises privacy concerns. |
| **Administrative Data** | Data collected as part of routine practice, thus less resource intensive than specific purpose collection. Continuous data collection supports analysis of trend. Potential for substantial population coverage.  | Potential for inconsistencies in recording autism diagnoses across different agencies, regions and over time. Undiagnosed individuals and those receiving services outside those the administrative system will be omitted from the data. |
| **Census** | Large-scale universal coverage. | Reliance on self-reports or parent/caregiver reports of a diagnosis. Variation in diagnostic practices can undermine the reliability of estimates. Infrequent collection. |
| **Systematic Review and Meta-Analysis** | Greater statistical power, increased precision in derived estimates. Pooled prevalence estimates more generalizable than single study estimates. Sub-group analyses to examine how prevalence differs by region, period, age group, gender, diagnostic criteria or study methodology, depending on availability of data. Cost-effective alternative to the primary data collection required for large-scale prevalence studies. | Poorly designed or methodological flawed studies would undermine the reliability of any pooled estimate. May be inappropriate to pool estimates with high levels of heterogeneity. Time-consuming and requires specialised expertise. |

# Appendix 3: Census of Population (2022) and National Disability Survey (2006) questions

## Census of Population 2022 Disability Questions

In the 2022 Census of Population, disability referred to the experience of at least one long-lasting condition or difficulty as reported. This data was gathered over the following two questions in the census form.

### Q15: Do you have any of the following long-lasting conditions or difficulties?

|  |  |  |  |
| --- | --- | --- | --- |
|  | 1 Yes, to a great extent | 2 Yes, to some extent | 3 No |
| a) Blindness or a vision impairment |  |  |  |
| b) Deafness or a hearing impairment |  |  |  |
| c) A difficulty with basic physical activities such as walking, climbing stairs, reaching, lifting or carrying |  |  |  |
| d) An intellectual disability |  |  |  |
| e) A difficulty with learning, remembering or concentrating |  |  |  |
| f) A psychological or emotional condition or a mental health issue |  |  |  |
| g) A difficulty with pain, breathing, or any other chronic illness or condition |  |  |  |

**Q16: As a result of a long-lasting condition, do you have difficulty doing any of the following?** *Include issues due to old age.*

|  |  |  |  |
| --- | --- | --- | --- |
|  | 1 Yes, a lot | 2 Yes, a little | 3 No |
| a) Dressing, bathing, or getting around inside the home |  |  |  |
| b) Going outside the home to shop or visit a doctor’s surgery |  |  |  |
| c) Working at a job or business or attending school or college |  |  |  |
| d) Participating in other activities, such as leisure or using transport |  |  |  |

### Reference:

Central Statistics Office (2023) Census of Population 2022 Profile 4 – Disability, Health and Carers. [Online]. Available from: <https://www.cso.ie/en/releasesandpublications/ep/p-cpp4/censusofpopulation2022profile4-disabilityhealthandcarers/> [Accessed 9th September 2025]

## National Disability Survey 2006 Autism Questions

The National Disability Survey (2006) gathered data on autism as part of the following two questions relating to intellectual and learning difficulties. Respondents were asked to report on difficulties that have lasted, or are expected to last, six months or more or that regularly re-occur.

### F2 Do you have any difficulty with interpersonal skills due to any conditions such as autistic spectrum disorders?

1. No difficulty
2. Just a little
3. A moderate level
4. A lot of difficulty
5. Cannot do at all

**F9 Which disease or illness is the MAIN cause of your intellectual or learning difficulty?**

1. Autistic Spectrum Disorder
2. Attention Deficit Disorder
3. Dyslexia or Specific Learning Difficulties (SLD)
4. Down Syndrome
5. Fragile X
6. Pregnancy or birth problems
7. Other
8. Don’t know or unspecified condition

**Reference:**

Central Statistics Office (2008) National Disability Survey 2006 First Results. [Online]. Available from: <https://www.cso.ie/en/media/csoie/releasespublications/documents/otherreleases/nationaldisability/National_Disability_Survey_2006_First_Results_full_report.pdf> [Accessed 9th September 2025]

# Appendix 4: Stakeholder Organisations

The table below provides the names of the stakeholder organisations that were consulted and were collaborators in drafting this report.

|  |
| --- |
| Table 1: Stakeholder Organisations |
| AsIAm |
| Irish Society for Autism |
| Neurodiversity Ireland |
| Department of Children, Disability and Equality |
| Health Research Board |
| National Council for Special Education |
| Health Service Executive |
| Central Statistics Office |
| Department of Education |

1. [NDA Advice Paper on Disability Language and Terminology - National Disability Authority](https://nda.ie/publications/nda-advice-paper-on-disability-language-and-terminology) [↑](#footnote-ref-1)
2. As noted by autism stakeholders who provided input into this paper, the most important tool for ensuring accuracy and consistency in autism assessment is likely to be the establishment of robust national guidelines on diagnostic practice. Such guidelines would support clinical decision-making across public and private settings and are standard in several other jurisdictions. The absence of such guidance in Ireland, particularly in the context of an unregulated psychology profession and widespread reliance on private diagnostic services, contributes to inconsistencies and challenges in prevalence estimation. The unmet demand for assessment, which may be higher for cohorts facing financial barriers accessing private services, exacerbates these challenges. [↑](#footnote-ref-2)
3. Schools receive additional resources based on their profile and they can decide on the distribution of these according to needs in their school. [↑](#footnote-ref-3)
4. Data provided directly to the NDA by DCDE. [↑](#footnote-ref-4)
5. Spectrum, a US-based autism-science news website, produced a global map of autism prevalence studies that has tagged studies based on which diagnostic criteria were used, as well as providing some methodological detail on each. See: [Spectrum | Global Autism Prevalence Map (spectrumnews.org)](https://prevalence.spectrumnews.org/) [↑](#footnote-ref-5)
6. See http://iarb.ie/ [↑](#footnote-ref-6)
7. Currently in Ireland a Census of Population is conducted every five years. [↑](#footnote-ref-7)
8. See [2011-questionnaire.pdf](https://www.scotlandscensus.gov.uk/media/gxndympo/2011-questionnaire.pdf) [↑](#footnote-ref-8)
9. Direct correspondence received from the Scotland’s Census 2022 Team in response to an NDA query on the rationale for removing the autism-related response option from the Census 2022 questionnaire. [↑](#footnote-ref-9)
10. Whilst recognising the limitations for the National Disability Survey to examine trends over time given the infrequency of the survey [↑](#footnote-ref-10)