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ACORNS TO TREES

SUPPORTING THE MEANINGFUL INTEGRATION OF ADULTS
WITH LEARNING DISABILITIES INTO MAINSTREAM SOCIETY



Fraser of Allander Institute

Learning Disability Data: Looking Beyond Scotland

Background report

May 2023

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The Fraser of Allander Institute

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Disclaimer

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The analysis and writing-up of the results was undertaken independently by the FAI. The FAI is committed to informing and encouraging public debate through the provision of the highest quality analytical advice and analysis. We are therefore happy to respond to requests for factual advice and analysis. Any technical errors or omissions are those of the FAI.

Introduction

It is important that we take stock and review what we know about learning disability data currently available not just in Scotland but across the UK, and further afar in countries that can offer useful comparisons and benchmarks. This background report will cover relevant data assets outside of Scotland. The aim is to support the consideration of different approaches and stimulate new ideas for how we enhance the evidence base in Scotland based on what is working elsewhere. It is also to help us identify where existing thinking on the continuous improvement of data relating to people with learning disabilities can be reinforced by experiences beyond Scotland. Finally, this work sets out to assist our ability to reflect on the common challenges faced globally and appreciate where these are not unique to Scotland.

Understanding data collected across the UK

Responsibilities for policies that impact on the lives of people with learning disabilities are largely devolved to Scotland. Therefore, it makes sense to look at whether other parts of the UK have taken approaches that Scotland can learn from.

England

Learning disability registers are held by GP surgeries in England and anyone over the age of 14 should be invited for an annual health check.¹

The *Health and Care of People with Learning Disabilities*, Experimental Statisticsⁱ published by NHS Digital for England is an example of how analysis of GP data can provide an important and evolving contribution to the evidence base.² The aim of this statistical publication is to provide information about the key differences in healthcare between people with a learning disability and those without. It contains aggregated data on key health issues for people who are recorded by their GP as having a learning disability, and comparative data about a control group who are not recorded by their GP as having a learning disability.

The latest release published in December 2022, reports that it covered 55.7% of patients registered in England and 0.5% of the patients included in this publication were recorded by their GP as having a learning disability in 2021-22. Data is only collected from participating practices using particular systems (EMIS and Cegedim Healthcare Systems) and is extracted through the General Practice Extraction Service.

The publication provides statistical information on topics such as coverage/prevalence, cancer screening, prescribing and health checks. It states that 71.8% of patients with a learning disability had a learning disability health check in 2021-22 and with the introduction of annual health checks for people with learning disabilities in Scotland, this report could be considered as an example of how similar information can be made publicly available on a routine basis in Scotland.

The Adult Social Care Outcomes Framework (ASCOF) is intended to be used both locally and nationally in England to set priorities for care and support, measure progress and strengthen transparency and accountability. It draws on a number of data collections where information is collected from Councils across England.³

Most recently published by NHS Digital as Official Statistics in October 2022 this resource includes a couple of outcome measures which are important considerations for the learning disability evidence base. Measure 1E looks at the proportion of working age adults who received support during the year, with learning disabilities, who are in paid employment and measure 1G covers the proportion of adults with learning disabilities who live in their own home or with their family. Whilst these measures are similar to statistics previously published for Scotland within LDSS by SCLD, the Adult

ⁱ Experimental statistics are official statistics that are in the testing phase and not yet fully developed. Users are made aware that they will potentially have a wider degree of uncertainty. The limitations of the statistics will be clearly explained within the the release.

Social Care Analytical Hub available through NHS Digital⁴ brings together the social care publications for England in one place and is perhaps an indication of the potential direction of travel now that LDSS is collected (but not yet published) as part of the Source Social Care data collection by PHS.

Wales

Data on people with a learning disability has previously been recognised as being poor in Wales⁵, with many common challenges persisting around definitional confusion and a lack of detailed population data and monitoring systems to ensure the needs of people with a learning disability can be understood and supported. In May 2022, the Welsh Government published a Learning Disability Strategic Action Plan 2022 to 2026⁶ which includes an action to scope the cost and benefits of establishing a National Learning Disability Observatory for Wales to support the development of a comprehensive body of evidence to inform policy and service planning.

Under the Social Services and Well-being (Wales) Act 2014⁷, local authorities are required to establish and maintain registers of people who are ordinarily resident in their area who are sight impaired, severely sight impaired, hearing impaired, severely hearing impaired or have both sight and hearing impairments which in combination have a significant effect on their day-to-day lives. Local authorities must also establish and maintain a register of children who are within the local authority's area and who are disabled, have a physical or mental impairment which gives rise, or may in the future give rise to, needs for care and support. Local authorities may also maintain a register of adults within their area to whom these same criteria apply.

While it's a legal requirement for local authorities in Wales to maintain disability registers, it is not compulsory for someone with a disability to register themselves with a local authority. This means that the number of people on the registers may be an undercount of the actual number of people with a disability. It is also known that local authorities do not maintain their registers in a consistent way, which makes it difficult to determine the reliability of the data recorded.

The Welsh Government have in recent years published annual statistics covering Local Authority registers of disabled people. This includes publishing the number of people on learning disability registers by local authority, service and age range.⁸ Similar challenges to related collections in Scotland have been encountered regarding data quality, with not all local authorities providing completed returns. The collection and publication of disability register data ceased after the 2022 release which was published in February 2023. This stated that there were 12,303 people on learning disability registers in Wales.

There will now be a move to an annual person-level data collection for adults which commenced from April 2023, alongside a refreshed person-level data collection for children. The person-level collections are intended to provide additional intelligence on adults, including more robust data on disability but won't include people who do not have a care and support plan, therefore will continue to undercount the actual number of people with a disability.

Northern Ireland

The Northern Ireland Department of Health publish annual hospital statistics covering mental health and learning disability inpatient and compulsory admissions data. The data is taken from the Mental Illness & Learning Disability (MILD) Census, which is carried out each year, and is a count of all mental illness and learning disability patients who are resident in hospital or on home leave at the

time of the Census.⁹ Information is collected from each hospital on the basis of age and length of stay. The Census is a snapshot of the resident population on 17 February each year. Whilst the data quality is deemed “very good” for its coverage of hospital inpatients based on a snapshot date, it has very limited utility when it comes to informing the range of policy matters which need to be considered when considering the lives of people with learning disabilities.

The Northern Ireland Statistics and Research Agency (NISRA) released results from the Northern Ireland Population Census 2021 covering health, disability and unpaid care in December 2022.¹⁰ The data shows that “Intellectual or learning disability (for example, Down Syndrome)” was reported as a long-term health condition by 16,900 people or 0.9% of the population. This was the first time that Northern Ireland citizens were able to explicitly report that they (or members of their household) live with a learning disability.

Previously data from the 2011 census covering residents who reported to have a “learning difficulty, an intellectual difficulty, or a social or behavioural difficulty” which had lasted, or was expected to last, at least 12 months (40,200 residents or 2.2 per cent of the resident population) was being used as an indication of learning disability prevalence.¹¹ There is no comprehensive register/dataset detailing the actual number of individuals with a learning disability in Northern Ireland, although there have been studies based on figures from Health and Social Care Trusts. Systems and consistency challenges have previously been recognised when collecting information across Health and Social Care Trusts, and similar to Scotland there is a general lack of disaggregated data for the learning disability population in Northern Ireland.¹²

UK wide

Mencap

Mencap is a UK wide learning disability charity working with people with a learning disability and their families and carers. They define a learning disability as:

“a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life. People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people.”

- Mencap (2023)

Mencap estimate that there are 1.5 million people with a learning disability in the UK, with 1.3 million living in England.¹³ They believe this equates to approximately 2.16% of adults in the UK and 2.5% of children across the UK living with a learning disability. The figures calculated use learning disability prevalence rates from Public Health England (2016) and population data from the Office for National Statistics (2020). Individual estimates are provided on the MENCAP website for adults and children with learning disabilities but only for England, Wales and Northern Ireland. From these statistics it is possible to deduce that the residual relates to Scotland and works out at approximately 59,000 adults and 25,000 children (0-17 years). Therefore, giving an overall Scotland population estimate of 84,000 individuals which is considerably higher than the estimates discussed through the sources of incomplete data on the learning disability population in Scotland in our related report.

Pupil data

In Scotland, a child or young person has an Additional Support Need (ASN) if they can't benefit from the education offered by their school or nursery without additional support for learning being provided. Special Educational Needs (SEN) is the term most commonly used by education services in England and Ireland. In Wales a new Additional Learner Needs (ALN) system is being introduced which at present means both a SEN and ALN system currently operate alongside each other. The ALN Act replaces the terms special educational needs and learning difficulties and/or disabilities (LDD) with this new term – additional learning needs (ALN) which is used to describe learning difficulties or disabilities that make it harder for a child to learn compared to children of the same age.¹⁴

With different systems and terminology used across the UK, it is perhaps not surprising that data collection categories across annual pupil data collections (i.e. school census exercises) also varies. For example, Scotland has a specific learning disability category, whereas the other nations across the UK have a wider range of categories relating to learning difficulties. (See references for examples from England¹⁵, Wales^{16,17} and Northern Ireland^{18,19}.)

Understanding international approaches to data collection and publication for people with learning disabilities

Countries praised at being at the forefront of learning disability data collection include Canada, Australia, New Zealand and the Republic of Ireland.²⁰ In many OECD countries it is common practice to collect disability data through population surveys. Most break-down disability into specific categories, often focussing on intellectual disabilities specifically, thus allowing for more granular analysis of individuals with intellectual disabilitiesⁱⁱ within the data.

Previous meta-analysis of international prevalence articles has highlighted a range of methodologies/definitions/classifications applied to administrative or national household survey data. A review of 20 studies across nine countries (Australia, Canada, China, Denmark, Finland, India, Norway, Taiwan and Sweden) showed that prevalence estimates of intellectual disabilities ranged between 0.05-1.55%.²¹ Whilst the previously cited study discusses the reasons behind the high level of variability; other research considers harmonisation such as the feasibility for common databases across Europe.²²

International Classifications

The World Health Organisation (WHO) maintain a range of international classifications and terminologies. These serve as the global standards for health data, clinical documentation and statistical aggregation.²³ In particular the International Statistical Classification of Diseases and Related Health Problems (ICD) and the International Classification of Functioning, Disability and Health (ICF) are used to support various data collections/surveys across the world, including those which cover capturing information about people with learning disabilities.

ICD

The ICD classifies disease entities and other health conditions to gather diagnostic information.²⁴ The next revision of the International Classification of Diseases (ICD-11) is now approved by the WHO and preparation for its implementation is underway across the UK.

The implementation and promotion of ICD 11 across all mental health services was an action within the Scottish Government's Mental Health Transition and Recovery Plan²⁵ and the first stage of implementation commenced in November 2022. NHS Digital have stated an assumption that ICD-11 will not be mandated for use across the NHS in England before April 2026, but to prepare for the

ii It is important to note that learning disabilities, as referred to in the UK, are classified as 'intellectual disabilities' or intellectual and development disabilities (IDD) in countries outside of the UK, while 'learning disabilities' refer to cognitive processing disabilities, known in the UK as 'learning difficulties' (e.g., dyslexia).

changes, they are currently running an ICD-11 pre-implementation project.

This latest ICD update was made available by WHO on 11 February 2022²⁶ and provides a common language that supports health professionals to share standardised information across the world. It is a source for identifying health trends and statistics worldwide, containing around 17,000 unique codes for injuries, diseases and causes of death, underpinned by more than 120,000 codable terms. By using code combinations, more than 1.6 million clinical situations can now be coded.

The term “learning disability” is unique in its use to the United Kingdom, which adopted that term around 2001 to avoid stigma surrounding the clinical term used at the time – “mental retardation.” The relevant term in ICD-11 is “Disorder of Intellectual Development” and it lists specific indicators for four levels of severity (mild, moderate, severe and profound). A provisional assignment is also described for infants or children under the age of four. This subdivision allows for more granular data, but it must also be noted that it is a cause for concern amongst some health and social care professionals who worry that it can create labels which potentially lead to inconsistency in terms of different meanings across a range of public services.

ICF

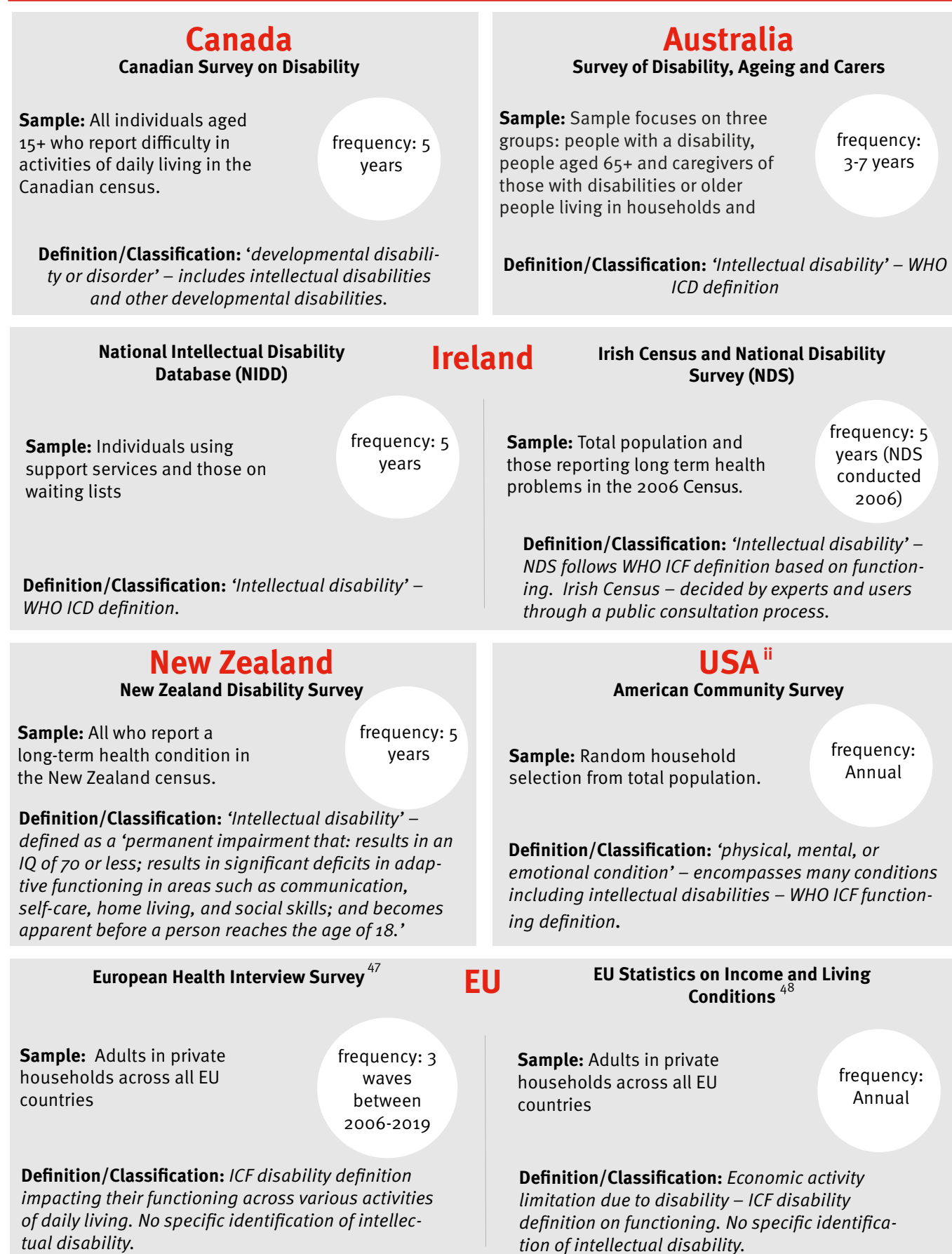
The International classification of functioning (ICF) is seen as complimentary and based on the same foundation as ICD.²⁷ It measures disability as a level of functioning based on the interaction of health conditions, environmental factors, and personal factors. It therefore considers the disability in a multidimensional context and is regarded by the WHO as the framework for measuring health and disability at both individual and population levels.

International Approaches to Data

We can potentially look to the practise of other OECD countries to better understand how others collect relevant data to help identify considerations for improving the evidence base in Scotland. The OECD is an international organisation focussed on social and economic progress, of which the 38 member countries provide useful comparisons and benchmarks on policy and economic challenges.²⁸

Diagram 1 (page 8) provides a summary of international data on learning disabilities.

Diagram 1: a summary of international data on learning disabilities



Canada

The Canadian Survey on Disability (CSD)²⁹ is the main disability survey in Canada. It is a national survey conducted every five years on all Canadians aged 15+ suffering from a long-term condition or health-related problem lasting six months or more. The sample is based on respondents in the Canadian Census who report difficulty in activities of daily living, resulting in an approximate sample size of 54,000 persons. The CSD was last conducted in 2022, with data due to be released at the end of 2023.

Disabilities are broken down into different categories including ‘learning, remembering or concentrating’. Respondents are then asked a series of questions relating to their condition that makes it difficult to learn, including a specific question on a professional diagnosis of a ‘developmental disability or disorder’ to indicate a learning disability. The examples provided in this question include Down’s syndrome, autism, Asperger syndrome and mental impairment due to lack of oxygen at birth. Follow up questions ask the age of diagnosis, the age at which daily activities began to be limited by the developmental disability and how much difficulty and disruption to daily activities the condition causes.

It is important to note that Canada’s use of ‘developmental disability’ encompasses a number of conditions including intellectual disability so the data collection for developmental disabilities will capture some individuals who have a developmental disability, such as Autism, Attention Deficit/Hyperactivity Disorder (ADHD/ADD) or Tourette’s Syndrome, but not an intellectual disability.³⁰ However, the CSD does provide a written answer box for the main medical condition causing difficulty, which allows respondents to provide the name of their intellectual disability so, provided this is recorded, it is possible to use the CSD to identify the prevalence of intellectual disabilities.

The National Benefits Authority in Canada refers to intellectual disabilities as ‘mental handicaps that prevent a person from fully utilizing his or her mental capacity, or reduces a person’s mental ability, making various mental and physical tasks difficult...typically diagnosed in people under the age of 18; their ability to function in their immediate social environment is a key indicator’.³¹ Such a reference would not be appropriate in Scotland. Other organisations and provinces across Canada opt for the American Association on Intellectual and Developmental Disabilities (AAIDD) definition (see references for example³²). This states an individual has an intellectual disability if three criteria are met:

1. Intelligence Quotient (IQ) is below 70-75
2. There are significant limitations in two or more adaptive areas (skills that are needed to live, work, and play in the community, such as communication or self-care)
3. The condition manifests itself before the age of 18

The CSD does include questions on learning disabilities, however in this context it is referring to conditions such as dyslexia, hyperactivity and attention problems. Information is also collected on various indicators such as medications and health care service use, education, labour force status and employment characteristics.

Other surveys including the Canada Income Survey³³ and General Social Survey³⁴ collect intellectual

disability data using the same ‘developmental disability’ question.ⁱⁱⁱ

Australia

The Survey of Disability, Ageing and Carers³⁵ in Australia collects data on three specific populations: people with a disability, people aged 65+ and caregivers of those with disabilities or older people. The survey is conducted at a household level and includes those living in private households, non-private dwellings and care accommodation establishments. The most recent survey was conducted in 2018 and has been conducted every 3-7 years since 1981. Sample households are randomly selected. 27,573 households and 1,175 care accommodations were sampled in 2018, resulting in a final sample of 65,805 individuals. The Survey of Disability, Ageing and Carers includes children with proxy interviews for children under 15.³⁶

A disability is defined as ‘*any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months*’. These limitations are then broken down into four categories of severity based on difficulty faced and the need for help.

The Survey of Disability, Ageing and Carers is broken down into 20 categories of disability, including ‘*difficulty learning or understanding things*’. Within this subsection ‘*intellectual disability*’ is a potential response to multiple questions, including the main condition causing difficulty, the condition requiring help or supervision, the condition causing social or behavioural difficulties and the condition causing speech difficulties. The Australian Bureau of Statistics (ABS) conducting this survey follow the WHO ICD definitions of intellectual disabilities.³⁷ However, this is not consistent across Australia, as other State and local level institutions follow the American Association on Intellectual and Developmental Disabilities (AAIDD) definitions. As previously mentioned, the key elements of the AAIDD definition are similar to ICD including low general intellectual functioning as measured by IQ score, difficulties in adaptive behaviour and the conditions developing before age 18.

New Zealand

The New Zealand Disability Survey³⁸ covers those reporting a health condition lasting six months or more in the Census. It surveys adults and children in both households and residential facilities and is conducted every ten years, following the Census. The most recent data collection was in 2013.

Intellectual disability is one of 12 potential answers to disability impairment type. The cause of impairment is also asked, which may provide further insight into the type of intellectual disability. New Zealand define intellectual disabilities as a ‘*permanent impairment that: results in an IQ of 70 or less; results in significant deficits in adaptive functioning in areas such as communication, self-care, home living, and social skills; and becomes apparent before a person reaches the age of 18*’.³⁹ According to the New Zealand Disability Survey data, 2% of the population have an intellectual disability. These rates are higher for males (3%) than females (1%).

Data on learning disabilities are also collected, where learning disabilities refer to ‘*a long-term*

ⁱⁱⁱ Note: State level systems tend to capture administrative datasets which identify only the portion of people with intellectual and development disabilities (IDD) who receive specific services or support. Administrative and claims data from federal and state health insurance programmes can offer an additional source for identifying the population beyond those receiving services and support. See reference 49.

condition or health problem that makes it hard in general for someone to learn'. The New Zealand Disability Survey additionally collects data on a number of social and economic indicators including the use of household help, health services, employment, transport, housing, safety, education, social care and leisure.

Ireland

Ireland has two main data sources for disability data: the National Intellectual Disability Database and the Irish Census.

The National Intellectual Disability Database (NIDD)⁴⁰, established in 1995 and annually updated, is the main source of intellectual disability data in Ireland. The NIDD defines intellectual disability using the WHO ICD definition. In 2017 the NIDD merged with the National Physical and Sensory Disability Database (NPSDD) to create one database on disability-funded services: the National Ability Supports System (NASS).⁴¹

Disability data collection is founded on support service usage. Based around the principle of 'minimal information with maximal accuracy', only data on demographic details, current service provision and future service requirements for day, residential and multidisciplinary support services is collected. The NIDD (now NASS) is expected to pick up all individuals with a moderate, severe or profound intellectual disability. However, those with a mild intellectual disability may not use support services and may be omitted. These missing individuals may be reported in the Census, if they choose to self-report and disclose their disability.

The Irish Census is another source of disability data. Since 2011, the Census has focused on seven disability categories, including separate categories for intellectual disability and difficulty with learning, remembering or concentrating.⁴² Provided the difference in these definitions are known by respondents, then the Census data can be used to record individuals with intellectual disabilities. The severity of disability, measured by 'a great extent' or 'to some extent' was also recorded in the most recent 2022 Census.⁴³

In 2006 an additional National Disability Survey (NDS)⁴⁴ was conducted, sampling those indicating disability in the 2006 Census. The NDS focussed on nine disability types, including 'intellectual and learning' disabilities. These disability definitions were based on the WHO International Classification of Functioning (ICF).

Conclusion – common themes

There is much to ponder from data collection practises across the OECD. The evidence considered in this report has highlighted many trade-offs when it comes to collecting data for people with learning disabilities. These mainly focus on cost, frequency/timeliness, and the level of data disaggregation.

Several countries disaggregate their disability data collection to specific conditions, providing options for individuals to report intellectual disabilities. Individuals with learning disabilities need to be able to record their disability as an individual answer and disability type, rather than as a group selection including other cognitive or developmental disabilities. This allows for visibility of people with intellectual disabilities within disability data.

Many datasets also collect information on other social and economic indicators, including employment, education and health. Collecting this data, in addition to disability, is beneficial as it provides wider information on the lives of these individuals, reducing the reliance on data linkage to other datasets and overall data collection costs, to achieve an overall insight into the lives of individuals with learning disabilities.⁴⁵

Definitions of learning disabilities – or intellectual disabilities as commonly used further afar – can be unclear and not consistent within, and across countries. Accurate self-reporting requires an understanding of what definition of intellectual/learning disability is being used in that particular survey. Therefore, due to potential misreporting, data collection may not accurately represent all relevant individuals. Inconsistencies in definitions also limits cross country comparisons if learning/intellectual disabilities are measured differently and reflect different groups of people in different countries.

Data collection tends to be based on either self-reporting disabilities or support service usage. There are limitations to both these methods. Service use may miss individuals with mild learning disabilities who are not using support services. These individuals will be picked up by self-reporting methods, if they choose to disclose their disability. However, as previously mentioned self-reporting requires understanding of definitions. Certain surveys ask about learning disabilities in terms of a formal diagnosis and there can be tensions between the medical and social models of disability categorisation. Not all individuals may have received a formal diagnosis, so will not be reflected in this data. Furthermore, due to fear of disclosure – predominantly based on a lack of trust in authorities, some people may choose not to report their disability at all. All of these can factors limit the accuracy of data collection.

Surveys that are not conducted at a national level may also be limited by who they sample. Additionally, samples in some countries are based on answers to disability questions in a census exercise. If individuals do not record a disability in the census, or fail to complete the census at all, then they will be missed from subsequent survey samples. Samples must include both adults and children living in both private and community care or residential settings to ensure no groups are missing from data collection.

The trade off with low levels of disability data disaggregation is the increasing complexity and time required to complete the survey. Surveys that collect lots of information and specify intellectual/learning disabilities can often be very lengthy, asking questions about multiple types of disabilities. These surveys may be difficult to complete and could require assistance to ensure the applicable disability questions are identified and answered correctly. Complex and lengthy surveys may result

in questions being missed, resulting in individuals missing from the data. Data collection may be better performed through interview, to reduce confusion surrounding questions and definitions. However, this can increase the cost and likely limit the frequency of data collection.

Timeliness is another trade-off as it is often not possible to run extensive surveys every year. As previously stated, many surveys are reliant on census identification, so are dependent on census frequency which is usually every 5-10 years depending on the country. A clear example of this is New Zealand which is one of the better examples of a database for individuals with learning disabilities. However, this is only collected every 10 years, and has currently not been updated since 2013.⁴⁶

An opportunity for Scotland?

Looking beyond Scotland, we have found that no country seems to have the perfect solution and there are many common issues and challenges when it comes to data relating to people with learning disabilities. Problems still arise surrounding unclear definitions, methodology and sampling issues, missing individuals and the trade-offs between cost, frequency and data extensiveness. Therefore, this highlights a need to not only be more innovative in Scotland by utilising what works best elsewhere but also to work smarter by considering what could be achieved through reviewing existing data collections to ensure appropriate levels of consistency and where value is best added.

The overall lack of systematic disaggregation of data does need to be addressed and to do this as efficiently as possible it should be informed by considering where the key evidence gaps presently exist. This can also be done alongside a look at the cost effectiveness of enhancing the current utility of existing data through more routine data linkage, against considering where individual collections may want to capture additional data such as social and economic indicators as standard. If this sort of activity can be effectively prioritised, then it could act as a springboard for Scotland to seize an opportunity to continuously improve and develop its evidence base to a point where it is recognised alongside nations who are leading the way.

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