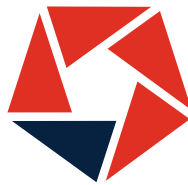




ACORNS TO TREES

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



UNIVERSITY of STRATHCLYDE
**FRASER OF ALLANDER
INSTITUTE**

Fraser of Allander Institute

Data on the lives of people with learning disabilities in Scotland

Short term actions for change



University of
Strathclyde
Glasgow

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Disclaimer

The analysis in this report has been conducted by the Fraser of Allander Institute (FAI) at the University of Strathclyde. The FAI is a leading academic research centre focused on the Scottish economy.

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.

Executive Summary

In 2020, the Fraser of Allander embarked on a programme of research looking at the barriers and opportunities for people with a learning disability in Scotland's economy and wider society. We found that throughout many areas of public life learning disabilities are absent from discussion and invisible in the data. This is the reason why as we now enter our second programme of work, setting out what we know and don't know about people with learning disabilities, and exploring how the data that we have available can be improved is a key area of focus for us.

Addressing the scale of inequalities faced by people with learning disabilities requires concerted action from government, industry and wider society. This is important if we are to move further towards a Scotland where people with learning disabilities and their families can realise their rights and live as an included and valued part of society. Key to this is the appropriate alignment of many areas of current policy development such as the new Learning Disabilities, Autism and Neurodiversity Bill, which is scheduled to come before Parliament in 2024, along with a new Human Rights Bill that will enshrine the UN Convention on the Rights of Persons with Disabilities into Scots law, subject to devolved competencies. Furthermore, the process of establishing a National Care Service is underway and both an Equality Evidence Strategy 2023 to 2025¹ and Scotland's first data strategy for health and social care² have been published in recent months.

Proposed legislation and new strategies can provide opportunity and optimism if implemented competently but the fact remains that effective action needs to be informed by a robust evidence base. To be able to achieve this, it is important that we take stock and review what we know about the data currently available not just in Scotland but across the UK, and further afar in countries that can offer useful comparisons and benchmarks.

Although there is plenty to consider and learn from elsewhere there are many common challenges and trade-offs between cost, frequency, and data richness to work through. For example, not everyone with a learning disability will identify as such, surveys might not be designed in a way that is accessible to someone with a learning disability, some people might not want to disclose their disability, and there might be confusion as to how we define learning disabilities.

Whilst our previous programme of work highlighted barriers (such as limited/inadequate data for people with learning disabilities) and inequalities, this programme is aimed at finding solutions and evidence to enable/lead change. This starts with this report, where after taking a closer look at the current learning disability data landscape, we've initially identified the following actions that could take place in the short-term to support the continuous improvement of the evidence base in Scotland:

1. Responsibilities to be clarified in relation to the publication of Learning Disability Statistics Scotland (LDSS) which has not been published since 2019 to ensure that this data is fit for purpose and continues to be published in full, with the added value of now being collected as part of the wider Public Health Scotland (PHS) SOURCE Social Care data collection realised.

2. Make the most of the potential of existing data, particularly the undertaking of more routine linkage of established existing data relating to the lives and experiences of people with learning disabilities. This should be prioritised and outputs made available on a regular basis.
3. The Scottish Government and partners in PHS and the National Health Service (NHS) should actively consider how they could collate relevant data from General Practices (GPs), alongside how data from the new annual health checks will be used to monitor and report on the health of people with learning disabilities. People with learning disabilities must have the opportunity to understand and contribute to the decision making process around this, including the bringing together of this data in order to build a national register of people with a learning disability.

These actions are concerned with making the most of data that does, or soon will, exist and is under the control of the Scottish Government and its public sector partners in Scotland. Longer term, we also need to consider where data does not exist, if/how it should be collected, and who should be responsible. This may include wider UK bodies, such as the Office for National Statistics. We will return to this in future reports.

Introduction

The September 2020 report from the Fraser of Allander's first programme of work helped set the scene in terms of data and policy. By the end of this research programme, we concluded that the evidence on which to base effective policy to improve the outcomes for people living with a learning disability is severely lacking. We suggested a series of recommendations for the Scottish Government to consider, including the following which highlighted the need for an enhanced evidence base with much better coverage for people with learning disabilities is required to inform policy and decision making.

Population data: *The Scottish Government should recognise that current data is not fit for purpose and they should examine approaches to build on existing data to enable understanding of the requirements of people with learning disabilities throughout their life course.*

- Fraser of Allander Institute (2021)

The importance of improved data cannot be underestimated as it would also be a requirement which crucially underpins the other five recommendations we made back in October 2021. Although we are aware of work which starts to consider how improvements can be made to existing data collections and an acknowledgement of where some of the data gaps exist, there remains a lot to be done in building a more complete and ultimately fit for purpose evidence base for supporting people with learning disabilities in Scotland. Therefore, for our second programme of work, one of the key topics of focus is data challenges and working towards possible solutions which could lead to more regular and successful continuous improvement efforts in this area.

This report starts by building on our previous output which highlighted that there are several incomplete datasets in Scotland, making it challenging to first and foremost estimate the number of individuals who have a learning disability. The report looks in a bit more depth at these specific sources of data and also highlights some others which may be of particular interest when planning improvement activity.

This report is accompanied by a separate but related publication, titled '*Learning Disability Data: Looking Beyond Scotland (Background Report)*'. It provides an overview of the definitions and data collected for people with learning disabilities in the other nations across the UK. It also summarises how these countries and other developed nations who are members of the Organisation for Economic Cooperation and Development (OECD) fair in terms of the availability of relevant data which can be routinely used to inform effective policy. Whilst this exercise has enabled us to capture some interesting learning points, which if were more frequently implemented in Scotland would help improve the learning disability data landscape, it also highlighted several common challenges which are shared across the globe.

With the Scottish Government having now published their analysis of the Learning Disability, Autism and Neurodiversity (LDAN) Bill pre-consultation exercise, we provide some reflections on the importance of evidence in relation to the topics highlighted.³

We conclude this report by offering some thoughts on what next for learning disability data in Scotland. A series of actions are described based on what we know about existing data and future plans in Scotland, and what we've learned about similar data in the rest of the UK and further afar.

These actions are considered through a lens of opportunity which the recent publication of Scotland's first data strategy for health and social care⁴ and the upcoming LDAN Bill may potentially provide.

One important point of principle in discussing data on the lives of people with learning disabilities is whether or not people with learning disabilities themselves are content for their data to be used in the way that is desirable for researchers and policy makers. Going forward, particularly where new data collection is proposed, it is extremely important that efforts are made to involve people with learning disabilities into the decision-making process.

Understanding and making better use of Scotland's data

Our first programme of work highlighted three sources of incomplete data on the learning disability population in Scotland. These sources were the pupil census which is collected and published on an annual basis by the Scottish Government (SG), Scotland's Census which is conducted ordinarily every 10 years by the National Records of Scotland (NRS), and data published by the Scottish Commission for People with Learning Disabilities (SCLD) through their Learning Disability Statistics Scotland (LDSS) publication which covers adults with learning disabilities who are known to Scottish Local Authorities.

Table 1 summarises these three sources of information that exist in Scotland. Further detail is in the data catalogue in Annex A.

Table 1: Main sources of population estimates for people with learning disabilities in Scotland

	Learning Disability Statistics Scotland	Pupil Census	Scotland's Census
Published by	Not currently published (previously Scottish Commission for People with Learning Disabilities)	Scottish Government	National Records of Scotland
Population captured	Adults known to local authorities. Also includes some people with autism	Children with additional support needs in publicly funded schools	People of all ages
Information drawn from	Local authority records	School management information systems	Self-reported by individuals/family members
Most recent estimate (date)	23,500 adults (2019)	11,800 children (2022)	21,000 adults (2011) 5,000 children (2011)
Known issues	Main issue is that data is not currently being published. Other issues include non-reporting of data by local authorities. Only refers to people known to local authorities which is likely to only include those drawing on social care services.	Number of possible issues, mainly around interpretation of guidance.	Known issues with under reporting in self-reported surveys. User testing for the 2022 census has led to a change in how the question is asked which may improve response rates.

As Table 1 shows, there are fairly well understood issues with each of the data sources. As we discuss later in this paper and our related report, these issues are not unique to Scotland and no country has a perfect solution to capturing the full scope of people who have a learning disability and may need to draw on additional support to ensure that their human rights can be met.

However, there are a number of opportunities to use the data collections that currently exist, even if they are imperfect, to extend our understanding of the lives of people with learning disabilities and where government policy can make a difference.

Our first recommendation relating to existing data in Scotland refers specifically to the Learning Disabilities Statistics Scotland (LDSS) dataset. The immediate challenge with the LDSS data is to find a way for it to be published at all. The data collection has successfully been incorporated by PHS into their SOURCE Social Care data collection but no further data has been published since 2019.

Recommendation 1: Responsibilities to be clarified in relation to the publication of Learning Disability Statistics Scotland (LDSS) which has not been published since 2019 to ensure that this data is fit for purpose and continues to be published in full.

Our second recommendation is in relation to the opportunities for data linkage.

A key strength of the school pupil census is that it collects variables suitable for linkage purposes. This includes Scottish Candidate Numbers which provide a unique identifier for each individual pupil. The pupil census has therefore been included in a range of secure data linkage projects such as successful research studies carried out by the Scottish Learning Disabilities Observatory (SLDO)⁵ using Scotland's Census data.

Going forward we need to see consistent and aligned reporting in post-school education data and continue to build the case for more routine linkage of education data overall. If the analytical teams within Scottish Government can work together to prioritise regular outputs which link pupil/student data, including outcome data, to the likes of wider health and social care data this will help add a much needed cross-cutting component to the existing evidence base.

Scotland's Census offers a much richer data source than simply analysing univariate population counts. For example, there are publicly available cross tabulations of disability with a wide range of demographic and socio-economic variables. NRS can also create new cross tabulations on demand. For data linkage, Scotland's Census is a valuable resource for cohort creation and can be used to identify data on groups with multiple disabilities, household members that live with people with learning disabilities, people in those households with caring responsibilities, and family structures within those households.

There is equally high potential for data linkage with the LDSS data. Over recent years SCLD have been working with PHS to include LDSS in the SOURCE Social Care data collection.⁶

As the data is now collected by PHS as part of a wider collection of social care data from health and social partnerships in Scotland, this should bring benefits such as the ability to facilitate data linkage through the use of the CHI (Community Health Index) number to wider health and social care data held by PHS and to information held by NRS such as mortality data at the level of individual person. These benefits will only be realised if the data is of sufficient quality and therefore any further review of LDSS which is necessary to ensure that it is fit for purpose should be prioritised. Overall, there would seem to be an opportunity to gather richer intelligence and improve the evidence base for people with learning disabilities in Scotland. We therefore hope that any existing challenges are worked through and an enhanced LDSS resource is made available as soon as possible.

Recommendation 2: Make the most of the potential of existing data, particularly the undertaking of more routine linkage of established existing data relating to the lives and experiences of people with learning disabilities. This should be prioritised and outputs made available on a regular basis.

There are also a range of other data sources of interest in Scotland.

These include the statistics which are published as part of Source Social Care dataset which was previously mentioned in connection with LDSS. The Learning Disability Inpatient Activity Report which is produced annually by PHS and the Carers Census, which is still a relatively new Scottish Government publication and therefore currently labelled as Experimental Statistics¹, are both useful when considering the different aspects of support people with a learning disability may receive during their lifetime. These are summarised in Table 2, with more detail in the Data Catalogue in Annex A.

¹ 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 release.

Table 2: Further information collected on those drawing on health and care services

	Insights in social care: statistics for Scotland	Learning Disability Inpatient Activity Report	Carers Census	Relevant GP data
Published by	Public Health Scotland	Public Health Scotland	Scottish Government	Not currently published
Population captured	People drawing on social care that are fully or partially funded by the Local Authority	Admission and discharges into/ from NHS hospital inpatient departments.	Unpaid carers	
Information drawn from	Local authority and Health & Social Care Partnership records	NHS Patient Management / Administration Systems	Local authorities and Care Centres	Scottish Primary Care Information Resource (SPIRE) system/tool
Most recent estimate (date)	21,500 people (2021/22)	155 inpatients (2021/22)	2,210 cared for people with a learning disability and 270 people with a learning disability and physical disability (2021/22)	n/a
Known issues	Does not include those self-funding. Those with multiple care needs, including a learning disability, may be recorded under a different care need. Not all areas provide data.			For individual level information to be available, GPs must opt in, and coverage is expected to be low. Depends on the accuracy and consistency of clinical coding by GPs.

The availability of relevant GP data to analyse is clearly a big topic for discussion which goes far beyond just looking at people with learning disabilities. However, one point in particular is worth noting at this juncture - the newly established Annual Health Check for People with Learning Disabilities.

The Annual Health Check for People with Learning Disabilities (Scotland) Directions 2022 provides a duty on Health Boards to provide annual health checks to all people in Scotland aged 16 and over who have learning disabilities.⁷ The Scottish Government (2022) defines an annual health check as ‘a targeted invitation for a yearly check-up of the person with a learning disability’s health’. These checks went live in Scotland from May 2022, with an original expectation that checks would have been offered by 31 March 2023. We understand that this date is now being revised.

The Directions impose a duty on Health Boards to ensure that annual health checks are offered to individuals aged 16 and over who are known by the Boards to have a learning disability, and those aged 16 and over who identify themselves as having a learning disability (whether or not that learning disability has been formally diagnosed) and regardless of whether it is mild, moderate, severe or profound). Health Boards must also take all reasonable steps to identify persons within their Health Board areas who are under the age of 16 and who have a learning disability, in order that an annual health check can be offered to them as soon as they attain the age of 16.

- The Scottish Government (2022)

Annual health checks will take place in primary care and should facilitate the ability for each health board to effectively hold a learning disability register to help monitor the health of people with learning disabilities over time. Depending on overall interest, identification and take-up of these annual health checks for people with a learning disability, the data which we would expect to be centrally collated and publicly reported could provide a further and potentially better annual indication of the learning disability population in Scotland.

Whether or not information from GPs, with or without additional information from the Annual Health Checks, should be collated as part of a data resource (as is the case in other parts of the UK) raises a range of issues around ethics and consent, and is not a question that an organisation like ours could or should answer. We therefore recommend that the Scottish Government opens up this question to stakeholders, particularly including people with a learning disability, to see if there is consensus on a way forward.

Recommendation 3: The Scottish Government and partners in PHS and the NHS should actively consider how they could collate relevant data from GPs, alongside how data from the new annual health checks will be used to monitor and report on the health of people with learning disabilities. People with learning disabilities must have the opportunity to understand and contribute to the decision making process around this, including the bringing together of this data in order to build a national register of people with a learning disability.

Outside health and social care settings, the data collection for Scotland’s Devolved Employment Services has recently moved to a new template aligned to a shared measurement framework which should provide more detailed data on employability support and outcomes for people with learning disabilities going forward.⁸ We will specifically cover employability support and related data in a future report as part of this programme of work.

Box 1: Scotland's Surveys

An obvious place to look for data on the lives of people in Scotland are the suite of surveys that the Scottish Government administer on an annual basis. These include the Scottish Household Survey (SHS) and the Scottish Health Survey (SHeS). Indeed, these surveys are used to inform the Scottish Government of how many people in Scotland have a disability.

However, despite asking some questions that look, on the surface, relevant to understanding the lives with people with learning disabilities, the questions as they stand are not fit for purpose. Nevertheless, there is potential for redevelopment.

In this section, we provide some background information on how the surveys are currently conducted and some thoughts for the future. The Scottish Surveys Core Questions (SSCQ)⁹ provide data on disability by pooling data from a set of common questions included in the Scottish Health Survey, Scottish Household Survey and Scottish Crime and Justice Survey (SCJS) from 2012 onwards. Each of the surveys include a set of around 20 core questions that provide information on the composition, characteristics and attitudes of Scottish households and adults across a number of topic areas including equality characteristics, housing, employment and perceptions of health and crime. Responses on these questions from all three surveys are pooled to provide the SSCQ dataset with a sample size of around 20,000 responses.

The surveys ask two questions to identify if a respondent has a physical or mental health condition or illness lasting 12 months or more and if any condition or illness reduces the respondent's ability to carry out day to day activities. It is likely that people will provide more detailed information about their health in a survey which is focused on the topic of health and wellbeing. This means that the preferred source for statistics on the limiting long-term physical or mental health condition indicator is the Scottish Health Survey.

Table 3: Scottish Surveys Core Questions 2019¹⁰ - Long-term limiting health condition by source survey

Survey	%	Margin of error
SSCQ	25.9	+/- 0.7
SCJS	23.4	+/- 1.2
SHeS	34.7	+/- 1.9
SHS	24.5	+/- 1.0

Unfortunately, at present these surveys offer very little to the learning disability evidence base. Responses to follow-up questions regarding condition type are usually collected verbatim and the interviewer then has to map this information to a pre-defined coded list which often fails to yield reliable data/insight on people with learning disabilities.

Ideally it would be helpful to consider developing a core question (included across all surveys and therefore capturing a considerable sample) which would provide further information on people with disabilities. As a minimum and as suggested by table 3 above, the redevelopment of the question set within the Scottish Health Survey is likely to prove fruitful, and therefore would be a good place to start. This should be informed by the current content review¹¹ of the Scottish Health Survey being undertaken by the Scottish Government.

Any survey redevelopment must ensure questions are presented with the correct context because a

learning disability is not a health condition and therefore asking about a person's learning disability status within the general health section of the survey is not appropriate. This was a point highlighted in the Scottish Government's recent analysis¹² of their content review of the Scottish Health Survey from 2024 onwards.

The SCLD also shared our feedback which strongly recommended removing any reference to 'mental handicap' in the survey as this is outdated language and not appropriate terminology. A more detailed follow up question related to impairment would be a more suitable way of disaggregating learning disability and the inclusion of the Scotland's Census 2022 question which has been tested might offer the best option going forward.

As well as a set of core questions, there are also harmonised questions which may be in more than one survey and are recommended for use. These questions are not asked in all Scottish Government surveys and therefore data is not pooled like it is for the core questions. There is a harmonised question for recommended use for surveys looking to collect more information on the way conditions and/or illnesses effect respondents. The question would follow the core questions on long-term limiting health conditions and ask whether the condition or illness affects the respondents in any of the following ways:

- Vision (for example blindness or partial sight)
- Hearing (for example deafness or partial hearing)
- Mobility (for example walking short distances or climbing stairs)
- Dexterity (for example lifting or carrying objects, using a keyboard)
- Learning or understanding or concentrating
- Memory
- Mental health
- Stamina or breathing or fatigue
- Socially or behaviourally (for example associated with autism, attention deficit disorder or Aspergers' syndrome)
- Other (please specify)
- None of the above (spontaneous only)

The Scottish Health Survey is currently considering alignment with this harmonised question. The fact that this question is not core and it is also difficult to ascertain with any certainty whether the respondent has a learning disability or not means that it potentially adds very little to the evidence base for people with learning disabilities. This would therefore seem to strengthen the case for any future survey re-design to consider following the disability and long-term health condition question from Scotland's Census 2022.

What Next? ‘Lead to Data Driven Change’

The Scottish Government previously stated their intention to make improvements to the evidence base through its autism and learning/intellectual disability transformation plan ‘Towards Transformation’ back in March 2021. Now in 2023, and over two years since its publication – there are very limited signs of progress being made. This is concerning and can probably be best demonstrated by the fact that LDSS has not been published since 2019. The Covid-19 pandemic will have had an impact and exacerbated data quality challenges. We therefore appreciate that a review of the dataset has been necessary to ensure that published data serve the best interests of those with learning disabilities. However, future plans to work towards re-dissemination remain unclear.

As we’ve stated in this report, considerable work has now taken place to incorporate LDSS within the PHS SOURCE Social Care data collection. This should bring added value and has the potential to further enhance the utility of the dataset. There has been no relevant statistical publication since this arrangement was put in place and responsibilities need to be clarified urgently to ensure that helpful data isn’t left in limbo and this resource can be fully utilised.

The Scottish Government’s new Equality Evidence Strategy 2023-25¹³ recognises a need to improve and expand data already collected. This is in line with our first programme of work and further reinforced in this report where we continue to see a lack of systematic disaggregation of data which severely hampers the ability to monitor the lives of people with learning disabilities. The limited data which is collected doesn’t represent a suitable evidence base for supporting effective policy making. Provision of services therefore runs the risk of being crudely informed by data which is available but not fit for purpose. One of the main reasons for this is due to major gaps in the data and although this report has highlighted several challenges which fall into this category, a more comprehensive gap analysis now needs to be undertaken to ensure resource can be focussed on prioritising what really needs to be known. It is imperative that any such exercise also thinks about data from a research perspective, as this can often be overlooked or seen as a secondary consideration. High quality research and the ability to do more of it based on relevant and robust datasets is vitally important to making a positive difference to the lives of people with learning disabilities.

Whilst our report titled ‘Learning Disability Data - Looking Beyond Scotland (Background Report)’, highlighted that there are several things Scotland can learn from elsewhere, it has also set out many common challenges and that nowhere seems to have yet achieved the ultimate answer. This should be embraced as an opportunity which can be supported by the process for the forthcoming Learning Disability, Autism and Neurodiversity Bill (see box 2). Through effective consultation, including most importantly with those with lived experience, there is a real opportunity to learn first-hand not only what data needs to be prioritised but how best to collect it from people with learning disabilities, autistic people and other neurodivergent people. It should provide the ability to focus in on what really matters and comes on the back of Scotland’s first data strategy for health and social care¹⁴ which was published in February 2023. This strategy aims to transform the way that people access their own data to improve health and wellbeing; and how care is delivered through system improvements. Together these highlight a significant opportunity to make the shift towards ensuring that people with learning disabilities are visible within health and social care data, which in turn could leverage improvements across other domains.

Box 2: Learning Disability, Autism and Neurodiversity Bill – Data reflections

The Scottish Government has committed to introducing a Learning Disability, Autism and Neurodiversity Bill. This will be aimed at upholding and protecting the rights of autistic people, people with learning disabilities, and other neurodivergent people. This Bill will also consider establishing a Commissioner to protect people's rights in practice.

In September 2021, the Scottish Government's Programme for Government stated that they would carry out scoping work on the remit and powers of the Bill. Therefore, ahead of a forthcoming formal public consultation, the Autism and Learning Disabilities Team within Scottish Government undertook initial scoping work on the Bill between May and July 2022. They ran 30 events with 18 different organisations (including national charities, Disabled People-led Organisations, and other advocacy groups) to gather feedback, information and to gain a better understanding of what people deem important when it comes to shaping the Bill. A Scoping Analysis based on this engagement was published by the Scottish Government in February 2023¹⁵ and they continue to be provided with input from three panels, which importantly includes a lived experience advisory panel to work with them throughout the Bill process.

The scoping analysis highlighted topics most frequently mentioned during the engagement exercise. These included and were not limited to - overcoming discrimination, increased inclusion, defining terminology, the risks of broad definitions, the need to adopt an intersectional approach, the transition from child to adulthood and alignment across legislation and services. This further underlines the importance of a better evidence base and ability to monitor the needs of people with learning disabilities, autistic people and other neurodivergent people.

Although not explicitly mentioned in the Scottish Government's Scoping Analysis document, it is important to recognise that the topics of interest for the upcoming Bill are all likely to have data related considerations or a requirement to be underpinned by good data in some shape or form. Whether this is ensuring that measurement is properly considered if new legal definitions are sought, or compelling evidence is available to support the establishment of new/stronger rights, or that relevant information can be collected to inform the discussion about establishing a Commissioner versus alternative models, data will play a vital role in determining what the Bill can achieve. At the same time the Bill itself presents an opportunity to enhance the evidence base by providing a vehicle that insists data improvements in this area are properly prioritised in the future.

Whilst research achieved through data linkage has facilitated several key insights to support the lives of people with a learning disability in recent years in Scotland, these can often be one-off exercises which take a long time to work through the relevant data access/application/information governance processes etc. It is therefore vital that as well as adding further depth to the learning disability data being gathered through current collections, similar to the efforts made to update the Employability Shared Measurement Framework¹⁶ used to underpin the reporting of data for people using Scotland's devolved employment services, the case also continues to be strongly made for prioritising more routine linkage of existing data in this area.

Whilst new strategies and potential legislation provides added optimism for progress in empowering people with learning disabilities moving forward, we hope that this report has highlighted the

availability of existing data sources. It is important that the feasibility frontier of these imperfect datasets continues to be examined and in turn further stimulate the appetite to develop the evidence base. The unlocking of primary care data, including the potential for a learning disability register to be collated through the introduction of annual health checks in Scotland, could play a big contribution to this but this can only be done with the understanding and consent of people with learning disabilities.

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Annex A – Data catalogue

The following outlines existing sources of data available in Scotland which contribute to the current learning disability evidence base. We have not covered every source which relates in some way or another to people in Scotland with a learning disability but instead tried to capture those which may provide the most value/detail at present. We hope to see improvements in the future and new sources established to fill key evidence gaps, including capitalising on more routine linkage of existing data. We will therefore treat this ‘catalogue’ as a live document/resource and periodically revisit to make updates where appropriate.

Learning Disability Statistics Scotland

The Scottish Commission for People with Learning Disabilities (SCLD) publishes [Learning Disability Statistics Scotland \(LDSS\)](#) which uses the term ‘adults with learning disabilities’ to include those adults with learning disabilities and/or on the autism spectrum who are known to local authorities in Scotland, regardless of the services they receive, and reported to the LDSS team. This means the data does not necessarily just cover the people who are using services. It also indicates there will be adults with learning disabilities not known to local authorities and possibly some who are known but not reported. These adults are not included in the reported figures.

The latest data collection guidance notes for this statistical publication advise that a learning disability is defined as stated in the Scottish Government’s learning disability strategy ‘[The Keys to Life](#)’. The last report was published back in 2019, where 30 out of 32 local authorities returned individual data to Learning Disability Statistics Scotland. One local authority provided aggregated data (Glasgow City Council) and one local authority did not return any data for this collection. The previous year saw 31 local authorities provide a data return for this collection.

Learning Disability Statistics Scotland data is available back to 2008, with the headline number for both 2018 and 2019 being around 23,500 adults known to local authorities across Scotland which in both years equated to 5.2 people with learning disabilities per 1,000 people in the general population or 0.5% of the population. This is the lowest the rate per 1,000 people has been over the course of time. However broadly speaking the rate has been pretty flat throughout, with it peaking in 2009, recording a prevalence of 6.5 people with learning disabilities per 1,000 of the general population. These estimates are widely considered to be an underestimate of the learning disability population in Scotland as not all adults with a learning disability are eligible for support. It is important to note that with the tightening of eligibility criteria, some people with more moderate support needs who may have been eligible for local authority provided support in the past, are no longer eligible and this may result in them not being picked up in LDSS.

The LDSS does not just provide a sole population estimate, it also provides demographic information and collects related data on topics such as where people live, employment status and whether individuals have attended further education.

Scotland’s Pupil Census

The [school pupil census](#) is used to collect information on all students attending publicly funded schools in Scotland. The exercise is undertaken annually and based on a mid-September census

date. The data which covers publicly funded primary, secondary and special schools is submitted by schools to local authorities, who then submit it to the Scottish Government.

Schools register if their students have additional support needs and include a record for each need. Learning disability, autism spectrum disorder and both specific and moderate learning difficulties are included as individual codes. This part of the data collection can act as a flag to signal which pupils need additional support based on their current educational setting.

Although a [guidance document](#) to support the data collection is published online and has been revised in recent years to provide updated information on reasons why pupils may receive additional support, there are a number of factors which may lead to inconsistencies with capturing the school population who have a learning disability.

The main reasons are the interpretation of the guidance itself, the variation in what might be deemed as “additional support” in different settings/availability of resources across the country and uncertainty about who is completing the annual census return. The responsibility may fall to one of, or a combination of teaching, support or admin staff depending on the school. This is a point which is particularly relevant when it comes to the recording of additional support needs data where there will be a range of different information being used to inform this part of the collection.

The data published as part of the 2022 school census shows that overall, there were 11,800 pupils recorded as receiving additional support needs (ASNs) due to having a learning disability. This equates to 1.7% of all pupils in 2022. Whilst overall pupil numbers have been increasing year on year over the last decade in Scotland, the number of pupils recorded as receiving additional support needs due to having a learning disability has fallen year on year. In 2012 this figure was almost 16,000 which equated to 2.4% of all pupils that year. This is interesting because the decrease in pupils recorded with learning disability as the reason for ASN seems to be unique in this regard, with other categories seeing an increase over time. In particular there have been notable increases for the ‘Other specific learning difficulty’ and ‘Other moderate learning difficulty’ categories so it’s possible that there has been a shift in the categorisation of pupils away from learning disability and towards one or both of these categories.

Scotland’s Census

Every household in Scotland has a legal responsibility to complete a census questionnaire. This means the census offers a detailed snapshot of the nation which Government and other services rely on census data to make important decisions. There has been a census in Scotland every 10 years since 1801, except 1941. The 2021 census in Scotland was moved to 2022 due to the impact of the COVID-19 pandemic.

There have been many changes over time, including how census data is collected and published. For instance, in 2011 this was the first time that people could complete their census online, with the majority now opting to take this option in 2022. Regardless of this change, many people with learning disabilities will have continued to require support in completing the questionnaire.

The 2011 census questionnaire asked respondents to tick all that apply from a list of health conditions which have lasted or are expected to last at least 12 months. Learning disability is one of the conditions listed with the example of Down’s syndrome provided in brackets. The 2011 census outputs show that just over 21,000 adults over the age of 16 ticked the box to say they had a learning disability. Slightly over 5,000 children (0-15 year olds) were also recorded as having a

learning disability. As pointed out in our earlier work these figures represent about 0.5% of their corresponding population, are likely to be an underestimate when compared to other sources and therefore should be caveated to highlight this, especially when considering the scale of the required policy response.

The [latest census questionnaire](#) took a slightly different approach in how it presented the options to the corresponding question for 2022. Instead of providing an example such as Down's syndrome directly next to the learning disability option, it provides a description – “a condition that you have had since childhood that affects the way learn, understand information and communicate”. For those people who were completing the questionnaire online a supplementary information box was available to view and provided a list of ten examples.

Scotland Census 2022 Household Questionnaire: Learning disability examples:

- Acquired brain injury
- Cognitive impairment
- Down's syndrome
- Fragile X syndrome
- Mild learning disability
- Moderate learning disability
- Neonatal brain damage
- Profound learning disability
- Severe learning disability
- Special needs

This change in approach was a result of topic consultation and questionnaire testing which concluded that respondents found it difficult to distinguish between 'Learning disability', 'Learning difficulty' and 'Developmental disorder'. The definitions and the example conditions helped respondents [differentiate between the three response options during testing](#). For example, it would help a respondent align autism to the 'Developmental disorder' option.

Topic level data collected through the most recent census exercise is not expected to be available until 2024. It's at this point we will be able to start to examine the potential impact of changes made to the relevant health condition question. As mentioned in the main report, Scotland's Census data is very sought after and has been used in many successful linkage projects. There are lots of [variables](#) and NRS offers support on request to researchers in scoping and designing custom [microdata](#) linkage projects.

Insights in social care: statistics for Scotland

The social care data in [these Experimental Statistics](#) are provided by health and social care partnerships in Scotland for people that are fully or partially funded by the Local Authority. This means that people entirely self-funding their care are not included. One further constraint in the reported statistics is that not all partnerships were able to provide information for every social care service/support.

The data can be split by social care client group and for 2021-22 it currently shows that 21,500 people or 97 per 1,000 social care clients who received social care services or support in Scotland had a learning disability. A closer look at the data broken down by age shows 845 people for the 0–17-year-old age group (or 215 per 1,000 social care clients) compared to 17,730 people for the 18–64 age group (or 336 per 1,000 social care clients). The numbers for all age categories of people with learning disabilities have generally been increasing over time since 2017-18 but an addition to the data items available since 2019-20, and the 2017-18 information only being available for the final quarter of the financial year for some services means that data is not directly comparable over the course of time.

Like a lot of collections this data is likely to undercount social care clients with a learning disability who receive social care services or support in Scotland in any given year. This is because the client group an individual is assigned to is determined by a Social Worker or Social Care Professional and is used as a means of grouping individuals with similar care needs. An individual can be assigned to more than one Client Group but only where the system being used to capture information can facilitate this so there may be people with other conditions that are not being assigned to the learning disability care group as it is not deemed the primary reason for why they are drawing on social care. The definition of a learning disability provided in the recording guidance used for this collection is consistent with the Scottish Government’s [‘Keys to life’ strategy](#).

Learning Disability Inpatient Activity Report

[This annual statistical release](#) became a standalone publication for patients with a learning disability in 2019. The information is published by Public Health Scotland, with the data sourced through their SMRo4 (mental health) returns for admission to and discharges from NHS hospitals in Scotland.

The latest trend data shows that the number of patients treated within what is described as the Learning Disability ‘speciality’ has decreased from almost 900 in 1997-98 to 155 in 2021-22. It is important to note that nearly six out ten admissions in the Learning Disability speciality between 2016-17 and 2021-22 were for respite care and not treatment.

Discharges for patients with a learning disability fell considerably from 4,700 in 1997-98 to 1,700 in 2005-06. Since then, the numbers have generally continued to fall but at a slower pace, reaching 401 in 2021-22. This was actually a slight increase on the previous year which reflects relaxation of measures in response to Covid-19. The overall downward trend is due to changes in service delivery, moving away from long-term hospital care towards more community-based care.

There are some other really interesting data in this annual release which supports the wider evidence base. This includes analysis of age of discharge, length of stay and the contrast between regular and irregular discharges. One statistical finding from this data source which needs to be highlighted, relates to the relationship between deprivation and the rate of learning disability inpatients. People with a learning disability who lived in the most deprived areas were 2.8 times more likely to experience an episode of inpatient care between 2016-17 and 2021-22 compared to those living in the least deprived areas. This finding is similar for patients treated for a mental health condition in psychiatric specialities where those from the most deprived areas were 3.2 times more likely than the least deprived to experience an episode of inpatient care in 2021-22.

Carers Census

Support given by unpaid carers is often overlooked and undervalued. As part of our first programme of work, we produced a [full report on learning disabilities and the value of unpaid care](#). We surveyed unpaid carers of adults with a learning disability and found on average, the support delivered by each unpaid carer in our sample would have cost the taxpayer £114,000 per year to deliver equivalent care.

The Carers (Scotland) Act 2016 took effect on 1st April 2018. The Act puts in place a system of carers' rights designed to improve consistency of support and prevent problems in order to help sustain caring relationships and protect carers' health and well-being. The Act also introduced the right to an Adult Carer Support Plan or Young Carer Statement based on each carer's desired personal outcomes and needs for support.

The Scottish Government's [Carers Census](#) collects a variety of information on unpaid carers being supported by Local Authorities and Carer Centres across Scotland. This information is being collected in part to help monitor the implementation of the Carers (Scotland) Act 2016. There have now been three publications of results covering 2018 up to 2021-22. Although the latest release for 2021-22 states that there have been improvements in data quality and completeness over the last year, there are still a number of challenges which persist with this collection, including many organisations implementing new systems to collate the required data. This means that current data is likely to undercount the true number of carers being supported by local services and since the data is still being developed, the results are currently published as Experimental Statistics. A number of future improvements have been identified and the Scottish Government is working with relevant organisations to enhance data quality and the usefulness of result for users going forward.

There were 42,050 unique carers being supported by local services identified in the Carers Census in 2021-22. The figures therefore do not represent all cared for people in Scotland. The statistics also report completed information on 35,880 cared for people (one person may also have multiple carers). The data currently published needs to be interpreted with care, as the 'unknown/missing' category makes up 27% of all cared for people. This compares to 6% (2,210 people) with a learning disability and 1% (270 people) with a learning and physical disability.

The data suggests that carers' needs vary slightly depending on the reason the cared for person requires care. The latest report states that people caring for someone with a learning disability appear to be slightly more likely than people caring for other groups to require short breaks or respite. However, caution should be exercised when drawing such conclusions due to the complexities involved when a carer cares for more than one person.

GP data

GP care data is currently accessed by Public Health Scotland using the [Scottish Primary Care Information Resource \(SPIRE\)](#). This tool which is installed in the majority of GP practices in Scotland, allows PHS to securely extract and report on the data held in GP systems. Since September 2021 aggregate data has been extracted unless GPs decide not to participate which means data coverage is high. However, the coverage of individual level data remains low (each GP practice must agree to individual level data being extracted) and PHS expects a gradual loss of SPIRE coverage over the coming months.

GP IT systems are in the process of changing, in particular how the data recorded are stored and managed. Work is ongoing with Scottish Government, NHS National Services Scotland and PHS to discuss and plan future infrastructure needs and data hosting solutions to ensure they can continue to access this data and improve the availability of information relating to general practice.

Access to primary care data is an on-going challenge and if this can be appropriately unlocked, it would provide a hugely important source of information, which through analysis of clinical coding could be utilised to help better understand the population with a learning disability in Scotland. We are aware that extracts of learning disability data at an aggregated level are now being taken from SPIRE by PSH to support such work.

Moving forward there will undoubtedly be further effort required to confirm what current coding can tell us about the severity of the population with a learning disability, as well as variations in coding practice to overcome. Scotland's latest [Digital Health and Care Strategy: Enabling, Connecting and Empowering](#) which was published in 2021, acknowledges the underlying issues of inconsistent coding and commits to focus on improving standards by fully implementing SNOMED or Systemised Nomenclature of Medicine, which looks to provide clinical and care IT systems with a single shared language.

There is a report currently available to GP Practices who are adopting the SPIRE tool which aims to help understand the co-morbidity profile of patients with learning disabilities. This shows the number of patients with a learning disability [Read code](#)² and aims to provide helpful information about recommended coding. It should be noted this report is run locally in the practice and no data are extracted.

² Read codes originated as a thesaurus designed specifically to enable general practitioners to code and record all relevant information arising from a patient encounter. Read codes have become widely used in general practice and primary care.

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