



## Learning Disability Statistics Scotland, 2019

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A National Statistics Publication for Scotland

### **Annex C, Data Quality Statement on ‘Statistics Release: Learning Disability Statistics Scotland 2019’**

This document forms part of a series of quality documents published by the LDSS team at SCLD to accompany the 2019 statistical release. Related information can be found in the ‘LDSS Statement of Administrative Sources 2019’.

Please find below a general discussion of data quality for the statistics ‘Statistics Release: Learning Disability Statistics Scotland 2019.’ Where there are data quality implications for specific data items within the Statistical Return, these are also outlined in the relevant section of the report and/or annexes.

#### **Operational context and administrative data collection**

##### ***Context***

Information is collected on adults with learning disabilities and/or are on the autism spectrum, known to local authority services who are aged 18 and over, or those aged 16 to 17 who are not in full-time school education.

For the purposes of this statistical return, people with learning disabilities are defined as in the Scottish Government learning disability strategy ‘The keys to life’:

People with learning disabilities have a significant, lifelong condition that started before adulthood, which affected their development and which means they need help to:

- Understand information;
- Learn skills; and
- Cope independently.

People with learning disabilities should have a range of support and services to meet the following needs:

- Everyday needs;
- Extra needs because of their learning disabilities; and
- Complex needs.<sup>1</sup>

This definition has been used in Scotland since ‘The same as you?’ and is broadly comparable with that used in England in the ‘Valuing People’ policy.<sup>2</sup>

All adults who match these criteria, regardless of the services they are currently receiving (if any) should be included. Adults with learning disabilities should be included in the local authority’s data return if they have had an assessment, even if this assessment has not led to any formal support.

The data does not include:

- Children under 16.
- Children aged 16 or 17 who are in full-time school education. The data provided on 16 and 17 year olds is likely to be a significant underestimate of the number of individuals in this group, as many individuals are likely to be in full-time education at this age.
- Adults with learning disabilities who are not known to local authorities (or who have not been in touch with the local authority in the last year).

The Statistical Return is derived from administrative data about adults with learning disabilities known to local authorities. This data is primarily

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<sup>1</sup> Scottish Government, 2013, ‘The keys to life: Improving quality of life for people with learning disabilities.’ Edinburgh: The Scottish Government available online at <http://www.scotland.gov.uk/Resource/0042/00424389.pdf>

<sup>2</sup> Department of Health, 2001, ‘Valuing People: A New Strategy for Learning Disability in the 21st Century’ available at <http://www.archive.official-documents.co.uk/document/cm50/5086/5086.pdf>

used by local authorities to keep records around assessment for care and support needs and the care and support offered to adults with learning disabilities. At aggregate level, the data is used by local authorities to monitor local demographic trends, plan and budget for care and support, monitor implementation of local and national policy priorities.

‘The keys to life’ set out 52 recommendations for action by the Scottish Government, local authorities, NHS Scotland and academic and voluntary bodies. An updated implementation framework for ‘*The keys to life*’ was launched in March 2019.<sup>3</sup>

SCLD recognises that with the changing policy context, data users, data suppliers and other stakeholders will want to ensure that the data provided in this publication continues to meet their needs and measure relevant outcomes. To this end, SCLD and Information Services Division (ISD) have been working together over the course of 2019 to merge LDSS into the Source Social Care dataset.<sup>39</sup> As part of this process, SCLD has worked with Scottish Government learning disability colleagues to update the LDSS data items to more closely align them with current policy and the new implementation framework for ‘*The keys to life*.’

### ***Data collection process map***

The LDSS team at SCLD (hereafter, SCLD) produces a [data guidance document](#) for local authority data providers for each annual data collection. This document explains the purpose and scope of LDSS and provides key definitions such as ‘learning disability’. It lists each data item for which data is collected, provides definitions within each data item and details all code values and definitions that can be used for each data item. The data guidance also outlines the timescales for the LDSS publication, from the start of the data collection to the report’s publication.

### ***Bias and error***

It should be noted that people with learning disabilities, like everyone else, have a range of skills, abilities and support needs. There may be some people with learning disabilities who are not known to local

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<sup>3</sup> <https://keystolife.info/wp-content/uploads/2019/03/Keys-To-Life-Implementation-Framework.pdf>

authority social services, and this may be for a range of different reasons, including but not limited to the following:

- The person is able to live independently without access to support that would be arranged through social work, and may have strong family and community support networks;
- The person and/or their family may not seek support from local authorities until the point at which crisis is reached;
- The person and/or their family may have rejected social work support;
- The bulk of the person's care package is funded by the NHS and therefore they may not appear in the dataset. This may be particularly true for people with both mental health issues and learning disabilities who live in forensic settings; and
- The local authority may be in touch with a person but may not have recognised that the person has a learning disability.

If an adult with learning disabilities has been assessed for a service by a local authority, the local authority is asked to include them in this Statistical Return, even if the assessment did not lead to the person receiving a service.

It is likely therefore that the sample of people with learning disabilities collected by LDSS for the purposes of this statistical return is biased towards those who require formal support services and away from those who have no, or few, support needs.

### ***Missing data***

In the 2019 data collection, 30 local authorities supplied individual level data and 1 local authority provided aggregate level data. North Ayrshire Council did not return any data about adults with learning disabilities for the 2019 collection. To present a picture for Scotland, figures provided by this authority in 2018 were used across the report and its annexes. North Ayrshire Council has indicated that headline figures have not changed greatly since 2018, so these figures should provide an accurate estimate for the overall picture in 2019. Glasgow City Council provided aggregate figures on all topics data was requested for. Some local

authorities were unable to provide data for some topics. Data users should be aware that incomplete data exists within individual data items; for example employment; and some individual level records that only hold limited data, for example, we may know only year of birth and gender for the person in question. Incomplete data within a data item, e.g. employment, can arise because a whole local authority may not have submitted any data on that item or there may be barriers to the local authority collecting the data or matching it to the relevant individual. These factors limited some of the analyses that might otherwise be possible and where this is the case, is highlighted at appropriate points in the report. Detailed information on data completeness for each topic is noted under each topic heading. Information on the local authorities that provided information on each topic is also available on page 6 of the main report.

As a general trend, data quality has improved significantly since 2008 across all of the data items collected, however, the introduction of GDPR in 2018 led to a rise in non-reporting across a number of data items in 2018. This was particularly true of items which are not routinely collected by local authorities through their Management Information Systems, such as employment and further education data. While completeness of further education data improved for 2019, completeness of employment data continued to decline. For a full summary of the change in data completeness between 2008 and 2019, please see page 44 of the main report.

## **Safeguards taken to minimise risks to data quality**

### ***Statistical manipulation***

No weighting or imputation work is currently undertaken on the data. It has been suggested by the UKSA that data weighting and imputation should be undertaken in order to mitigate the effect of missing values. In 2013 the Office for National Statistics Methodology Advisory Service carried out a feasibility study for data weighting and imputation. The report did not recommend these statistical methods be used on the dataset. Rather, the team should work more closely with local authority data providers to secure data of as high quality as possible. The team also worked with colleagues at the Scottish Government's Peer Review team to gain advice and support on managing missing data values. The Peer Review team also suggested that weighting and imputation may

not be beneficial and that further work to continue to improve the quality of the data may be a better alternative.

In early 2016 a national approach to scope a weighting methodology to reduce the impact of non-response bias on the data was undertaken by the Methodology Advisory Service from the Office for National Statistics funded by the Quality Improvement Fund. This study found that the use of a weighting schema to tackle non-response bias and differential missingness would not be appropriate for short-term time series analysis. The ability to analyse LDSS data over longer periods of time and between years is of value however and further work to determine a methodology capable of doing this is ongoing. Further information can be found in the National Statistics Assessment section of the main report.

### ***Duplicate data***

LDSS takes all reasonable steps to ensure that we do not include an individual in the collection more than once (duplicate data).

If an adult is funded by one authority but they live in another authority, their record should be supplied by the funding local authority. Where there is joint funding for an individual, the main funder should submit data for the individual in question. Where it is unclear as to whom the main local authority funder is, local authorities are required to negotiate between themselves as to who should submit the data on the person in question to minimise the risk of duplication. However, it is possible that this process is not undertaken, or as robust as possible, therefore some level of duplication may remain.

### ***Data guidance document and LDSS team support***

The data for LDSS comes from 32 different local authority data suppliers. This means there is a risk of inconsistent data recording across the data suppliers for each data item that would undermine the reliability of the national dataset. The LDSS data guidance document (see page 3) provides local authority data suppliers with clear and comprehensive guidance on what LDSS aims to do, its scope and definitions of all data items and value codes within them.

This ensures that all 32 data suppliers are coding their information consistently. An example of this is in the recording of accommodation type for adults with learning disabilities. During previous collections, it has been apparent there have been different understandings of specific

accommodation types, particularly in the difference between 'supported accommodation' and 'mainstream housing with support'. The LDSS data guidance provides clear definitions of these accommodation types against which data suppliers can code their data. If data suppliers are still not sure they are coding their data according to the national standard, the LDSS team at SCLD is available to support their questions and ensure the data is coded correctly.

### ***Implications for accuracy and quality of data***

Where local authorities do not submit data for specific data items, this has an effect on policy monitoring and evaluation at national level as only a partial picture of progress can be supplied. It may prevent people with learning disabilities, family carers and local organisations from building an accurate picture of the situation in their local authority. It may impact on local third sector organisations' ability to provide evidence for funding applications.

For the previous four collections LDSS has collected CHI data from local authorities. This allows for greater alignment with the Source dataset and enables learning disability data to be embedded in wider social care data collection.

The 2019 LDSS Statistical Release is the fourth to be published under this new system of collection using ScotXed. This change to the collection methodology has, for the most part, led to increased standardisation and improved data quality due to data provider familiarity with the system, alignment with other social care data returns, in-built validation checks and improved data feedback.

### **Communication with data supply partners**

#### ***Data requirements for statistical purposes***

SCLD has engaged with local authority data providers to identify how data for LDSS is extracted from their management information systems. Most local authorities have a dataset that includes data for all data items which is updated each year by asking service providers (such as day centre staff, local area co-ordinators etc.) if specific information has changed for the people included in the dataset. Some local authorities have developed systems that update service information more regularly and from which the data supplier can simply extract data for the collection period and therefore reduces the burden for the data supplier by making the collection less manual.

SCLD and Information Services Division (ISD) have been working together over the course of 2019 to merge LDSS into the Source Social Care dataset. Final guidance for data providers will be issued in January 2020, and will take effect from April 2020. Data providers will submit LDSS data to ISD via their GlobalScape system as part of the Source Social Care survey from September 2020. The initial tranche of data will allow for data quality issues to be uncovered and addressed.

The merger ensures that learning disability data is captured within a routine health and social care data collection. This will add value to the data by allowing for linkage with other topics within the Source dataset, as well as linkage with other health and social care datasets.

### ***Legal basis for data supply***

LDSS is not a statutory data collection, so there is no legal requirement for local authorities to make a submission for the LDSS collection.

However, LDSS is included in an annual letter sent out by the Scottish Government's Analytical Services Division to Directors of Social Work detailing all Social Care surveys that are due for completion. This is to ensure that the Scottish Government meet their pre-announced schedule for publication of National Statistics.

### ***Data transfer process***

Local authority data suppliers extract administrative data from their management information systems and collate it with non-routinely collected data such as employment and further education data. The 2019 collection is the fourth where data has been collected through the Scottish Government ScotXed Team's ProcXed system. The data supplier uploads the data to the ProcXed system, for which they are provided a password by the ScotXed team. SCLD is also issued with a password by the ScotXed team which allows the team to check the progress of uploads and approve the submissions. Once all the data has been uploaded, SCLD can then download the data from the ProcXed system. Further information can be found within the main statistical release.

Data submitted for the LDSS collection is collected and held securely within the Scottish Government's ProcXed system. SCLD access and download the data through the ProcXed.net system which provides a secure file transfer facility. All of the data items collected through the

LDSS are transferred, however, the CHI number received by the SCLD is encrypted by the ProcXed system before transfer.

SCLD store the data in two separate files. One file contains only the personal identifiable data (date of birth, postcode, CHI, unique ID). Another file contains all the census data along with age, datazone and other geographies. This second file is a pseudonymised file and therefore contains no data which would allow an individual to be identified.

Access to the domain where the secure server where the data is held is limited to the LDSS team (two people), who ensure adherence to General Data Protection Regulations and UKSA Code of Practice confidentiality principles to maintain data security.

Small value statistics (values of 5 or fewer) are not made publicly available in the LDSS report to help ensure individuals' identities are not disclosed. Values of 5 or fewer are rounded to 0 or 5 and one other value in the rounded value's row and column are also rounded to the nearest 5 to prevent disclosure through differencing (subtracting the sum of all the numbers in a column or row that have not been rounded from the total to determine the true value of the rounded number).

### ***Sign off arrangements by data suppliers***

In 2019, local authorities submitted their data to LDSS via the ScotXed Team within Scottish Government using their ProcXed system. The 2019 LDSS Statistical Release is the fourth to be published under this system of collection. The ProcXed system has in-built data validation checks that allow each local authority to ensure the data is valid before they submit it. Additionally, the ProcXed system provides the local authorities with frequency tables and the opportunity to carry out their own analysis. Local authorities cannot submit data without it being approved by the LDSS team.

### ***Mode of communication with data supplier contacts***

For the 2019 collection period, the LDSS team worked directly with individual local authorities to address their specific needs as and when they arose. Communication channels were kept open and local authorities were regularly reminded of the opportunity to raise issues directly with SCLD or the ScotXed team.

## ***Views and experiences of statistics users***

The statistics fall broadly into the following categories of use as defined in the UK Statistics Authority's Monitoring Brief 6/2010 "The Use Made of Official Statistics."<sup>4</sup> Information on use comes from responses to a survey of users undertaken in 2013, from the stated purposes of the statistics collection by the Scottish Government and from the knowledge and experience of the statistical producer team.

The reference numbers provided below (e.g. ii.a.) are those outlined within this Monitoring Brief.

i. Informing the general public's choices:

- d. about the state of the economy, society and the environment
- e. about the performance of government and public bodies

The statistics on adults with learning disabilities known to local authorities provide accessible summaries about people with learning disabilities to help inform the public, including people with learning disabilities and family carers themselves. The statistics also play a role in making the public aware as to the progress made towards the implementation of the Scottish Government's learning disability policy.

ii. Government decision making about policies, and associated decisions about related programmes and projects:

- a. policy making
- b. policy monitoring

The statistics on adults with learning disabilities known to Scottish local authorities provide an evidence base both for government policy making about adults with learning disabilities and monitoring of the implementation of government policy. For example, 'The same as you?' said that no-one should have a hospital as a home and that adults with learning disabilities should be able to live independently in the community. Data on accommodation type collected for the purposes of this release can play a part in monitoring progress.

iii. Resource allocation – typically by central and local government

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<sup>4</sup> UK Statistics Authority, 2010, Monitoring Brief 6/2010 available at <http://www.statisticsauthority.gov.uk/assessment/monitoring/monitoring-reviews/monitoring-brief-6-2010---the-use-made-of-official-statistics.pdf>

A survey of the users of the statistics in 2011 indicated that local authorities are a key customer. Local authorities reported that they use the statistics to review practices, plan services, provide demographic information on adults with learning disabilities, provide information to social work management and to provide information on local outcome indicators and performance indicators.

iv. Informing private sector commercial choices:

a. targeting local markets

The statistics on adults with learning disabilities known to Scottish local authorities may be valuable to private sector or social enterprises wishing to provide services to people with learning disabilities in a given area. This is particularly the case in light of the introduction of self-directed support in Scotland, wherein adults with learning disabilities, often together with their families, may choose the mechanism by which their support is delivered, for example through a direct payment.

vi. Supporting third sector activity:

a. lobbying

b. funding applications

The statistics on adults with learning disabilities known to Scottish local authorities are known to be used by third sector organisations to support campaigning activity, for example on access to employment, further education and to support family carers, and as evidence to support funding applications for projects with adults with learning disabilities.

vii. Facilitating academic research

A survey of users of the statistics in 2011 demonstrated that academics are using the data to provide context for, and to inform, research agendas.

## **Quality Assurance principles, standards and checks applied by data suppliers**

### ***Data suppliers' quality assurance checks***

As mentioned above, where local authorities do not routinely collect data for LDSS for areas such as employment and further education, the data supplier must contact service providers and record this data manually against each person with learning disabilities in the local authority area.

This is then used as a baseline of information for the following year, which the data supplier asks service providers to update with new information where necessary e.g. where individuals have got a job, changed job type or become unemployed. This verification process, whereby contacts from the data supplier and service providers work closely together, helps ensure that the information being recorded about people with learning disabilities most accurately adheres to the LDSS guidance. In doing this, the data not only meets internal quality assurance in terms of accuracy within each local authority area, but it also meets external quality assurance by helping ensure the data recorded across local authorities is consistent.

Each year, the LDSS team identify changes in the data per data item for each local authority. Where there has been a change in the data that is regarded as significant or unusual, the LDSS team ask the relevant data supplier to confirm the data is correct and if so, to provide an explanation for the change. The most common explanations are internal audits of management information systems and changes to recording practices.

## **Producer's quality assurance investigations and documentation**

### ***Producer's own quality assurance checks***

When data suppliers have submitted their data, the Evidence & Research Officer at SCLD applies quality assurance checks to verify the data as a separate stage from that carried out by the data suppliers.

These checks include:

- Ensuring only adults with learning disabilities aged 16 and over not in full time school education and known to local authorities are included.
- Ensuring people who have been removed from the dataset in previous years do not reappear by checking birthdates and querying increases in older people since the previous year.
- Comparing outputs of specific items to each other to ensure they have been coded correctly. For example, cross tabulating 'employment status' by 'time spent working' will confirm that everyone who doesn't have a job has been recorded 0 for 'time spent working' and everyone who does have a job will be recorded 1 or more for 'time spent working'.

## **Strengths of administrative data**

LDSS publishes statistics about adults with learning disabilities known to Scottish local authorities. Consequently, the local authorities themselves were identified as best placed to supply this data. Although local authorities use different management information systems and have different working practices in data management, they have all been in a position to supply the relevant data each year. Furthermore, a number of local authorities have used their participation in this data collection as an opportunity to invest resources in their management information system and routinely collect more data than they had previously. This means the data held is more accurate in terms of its coverage and accuracy.

As mentioned on page 6 of this document, local authorities as data suppliers are best placed to ensure one record is returned for every adult with learning disabilities without duplication within their own records or by other data suppliers. Furthermore, local authorities have also demonstrated an ability to collate routinely held data such as year of birth and ethnicity with non-routinely held data such as employment status and further education. This is largely due to the strength of the relationships between local authorities and service providers. Local authorities are able to use identifying information such as name and address to match their records to those of service providers and other bodies such as advocacy organisations and colleges to collate non-routinely collected data.

## **Limitations of administrative data**

As outlined on page 4 of this document, the LDSS dataset has been affected by missing data i.e. where local authority data providers do not know specific pieces of information. The proportion of missing information within the national dataset as well as exactly what information is missing can vary significantly from year to year. This 'differential missingness' impacts on the quality of the statistics because the base of known information will be different each year.

Consequently, fluctuations in for example, the proportion of people who have a job may reflect an actual increase or decrease in people who have a job or it may simply be attributable to a change in the base of known information for employment, therefore altering the proportion of people with a job.

The LDSS team recognise the value of time series analysis of the LDSS data, particularly in identifying trends over time and relating them to Scottish Government strategic priorities. In early 2016 a national approach to scope a weighting methodology to reduce the impact of non-response bias on the data was undertaken by the Methodology Advisory Service from the Office for National Statistics funded by the Quality Improvement Fund. This study found that the use of a weighting schema to tackle non-response bias and differential missingness would not be appropriate for short-term time series analysis. The ability to analyse LDSS data over longer periods of time and between years is of value however and further work to determine a methodology capable of doing this is ongoing. Further information can be found in the National Statistics Assessment section of this report.

### **Comparability with other statistical outputs**

There are a number of other statistical outputs in Scotland relating to people with learning disabilities against which the coverage of LDSS can be compared. However, it should be noted that the data used for these outputs are collected according to different methodologies and have different scopes so are therefore not directly comparable with LDSS.

It is not possible at this point to know how many people with learning disabilities there are in Scotland who are not known to local authority services, beyond assessing prevalence reports from international and UK studies. It was suggested in 'The same as you?' that there may be up to 120,000 people with learning disabilities in Scotland, based on such studies.

Further context is provided by the 2011 Census for Scotland. Statistical outputs show that there were 21,115 people with learning disabilities aged 16 and over in 2011.<sup>5</sup> Further analysis of the 2011 Census data on learning disability was published by the Scottish Learning Disabilities Observatory in 2016.<sup>6</sup> This showed that there was 21,115 adults with learning disabilities in Scotland. These figures are lower than the comparable totals from LDSS, however caution must be exercised when making comparisons due to the different methodologies and inclusion criteria used by the statistical producers.

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<sup>5</sup> Scotland's Census 2011, Table DC3106SC:  
<http://www.scotlandscensus.gov.uk/ods-web/standard-outputs.html>

<sup>6</sup> <https://www.sldo.ac.uk/reports-publications/reports/>

Further information on the comparability of other UK data collections on adults with learning disabilities can found within the main statistical release.