



## Learning Disability Statistics Scotland, 2018 Provisional Statistics

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A National Statistics Publication for Scotland

## LDSS, Statement of Administrative Sources 2018

This document forms part of a series of quality documents published by the LDSS team at SCLD to accompany the 2018 statistical release. Related information can be found in the other quality documents 'Annex C: Data Quality Statement on 'Statistics Release: Learning Disability Statistics Scotland 2018'.

To comply with the principles of quality, trustworthiness and value in the <u>Code of Practice for Official Statistics</u> (more specifically Q1.2, Q1.7, T4.5, T4.6, T6.1, T6.4, V4.5 of that code) SCLD publishes a 'Statement of Administrative Sources' to accompany the LDSS statistical release. This statement includes a list of the 'names' or 'titles' of all the quantitative information systems which are in operational use throughout the organisation, distinguishing between:

- Those which are already used for both internal and external administrative/management purposes as well as for statistical purposes;
- Those which, currently, are used only for administrative/ management purposes but which have the potential to be used, additionally, for statistical purposes.

## **Collection** – a short outline of the process through which the system's underlying 'raw data' are captured.

Local authority social work services collect and store data about people with learning disabilities and/or on the autism spectrum in their area or for whom they fund support in another geographic area, especially (but not always) if those individuals have been assessed for some kind of support from the local authority. The type of database used to record information about people with learning disabilities and/or on the autism spectrum varies from local authority to local authority, however, in general local authorities use either a CareFirst system or SWIFT system.

The Scottish Commission for Learning Disability runs the LDSS Project. The Evidence and Research team releases Data Guidance at the beginning of each collection year (March to April), requesting that each local authority supplies values across 20 data items about each anonymous individual with learning disabilities in their area or for whom they fund support outwith the area. Local authorities enter values onto a pre-prepared Microsoft Excel or Comma Separated Value file and submit the data to the LDSS team by an agreed date (end of July). Some of the data items are readily accessible to local authorities from their CareFirst or SWIFT systems. However, other data items require local authority staff to contact colleagues from other departments or from external organisations to collate and supply the data, for example:

- College attendance,
- Local area co-ordination use,
- Advocacy.

Local authorities may enter a value of 'unknown' where they do not have the relevant information about an individual.

**Application** – a description of each of the main applications/uses to which the administrative/management data are put before they are transformed into official statistics (for example, operational monitoring, resource allocation, or performance measurement).

Local authorities collect and record data on people with learning disabilities for a number of different purposes, including needs assessment, service delivery, operational monitoring, resource allocation, performance measurement and other purposes. Access and dissemination – a summary of the arrangements put in place for sharing and disseminating the administrative/ management data, either inside or outside the organisation, during the period before they are converted into official statistics – whether via a hardcopy, an intranet, access to a database, or whatever. The details provided should cover the range, nature and timing of such access.

The LDSS team within SCLD (hereafter, SCLD) releases Data Guidance at the beginning of each collection year (March to April), requesting that each local authority supplies values across 19 data items about each anonymous individual with learning disabilities in their area, or for whom they fund support outwith the area. Local authorities enter values into a pre-prepared Microsoft Excel or Comma Separated Value file and submit the data to the ScotXed team via their ProcXed system by an agreed date. This is usually the end of July, but can be extended (usually to the end of August) if local authorities are having difficulties submitting returns. 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 ScotXed team.

SCLD receive the data from the ScotXed team via a secure download from the ProcXed system. The SCLD team then separate identifying information (postcodes and date of birth) from the rest of the data. Both are then stored separately on a secure server, which can be accessed only by the statistical team (two people), all of whom ensure adherence to General Data Protection Regulations and UKSA Code of Practice confidentiality principles to maintain data security.

Once the data has been received by SCLD (usually between August and October) the cleaned data are analysed, converted into national and local tables and a statistical report is prepared. Local authorities and the Scottish Government are given pre-release access to the statistical report 7 days before the report is published.

**Non-statistical publication** – a summary of any exceptional arrangements made for placing the administrative/management data in the public domain during the period before they are converted into official statistics. This should cover the reason for such publication and the nature and timing of it.

The data are not placed in the public domain before they are converted into official statistics.

**Statistical publication** – a listing of each of the 'official statistics' or 'National Statistics' series derived from each system.

SCLD is only responsible for producing the following official statistics publication on behalf of the Scottish Government.

## • Learning Disability Statistics Scotland

As such, SCLD only has access to the administrative data about people with learning disabilities supplied by local authorities. Local authorities may submit data items also collected in the LDSS return to other statistical collections on the request of the Scottish Government. SCLD does not have a record of these currently.

**Synergies** – a mapping which explains the relationship between any public manifestations of the administrative/management data, and any subsequent statistical releases or publications.

The LDSS data are not used to inform any other statistical products.

**Security/data protection arrangements** – organisations are also encouraged to link their Statements to the more detailed metadata documentation described in Annex B. The extent to which this metadata can be compiled will give a good indication as to whether sound judgements can be made on the suitability of such systems to provide relevant statistics that are fit for purpose.

The quality of official statistics derived from administrative/management systems depends to a large extent on having a clear description, and thus understanding, of the processes through which both the original data are collected, and the resultant statistics are produced. The essential requirement is to provide a detailed and easily accessible 'process map' which describes the complete chain of production – starting with the original collection process and ending with the delivery of the final statistical product – through provision of the following metadata.

## Recommended metadata fields:

Statistical end-product

• Title of the statistical product derived from an administrative/ management source

Learning Disability Statistics Scotland

 Name of the organisation responsible for this statistical endproduct

Scottish Commission for Learning Disability (on behalf of the Scottish Government)

5th Floor, Suite 5.2 Stock Exchange Court

77 Nelson Mandela Place Glasgow

G2 1QY

0141 248 3733

• Name/email address of contact point for this product

Lorne Berkley, Evidence & Policy Manager, <a href="https://www.lorne.berkley.co.uk">lorne.b@scld.co.uk</a>

Ruth Callander, Evidence & Research Officer, ruth.c@scld.co.uk

Administrative/management source or system

## Name/title of the original administrative/management data source

The LDSS collection requires local authorities to compile information on individuals, usually from a number of different data sources. Data may come from social work departments, further education institutions, advocacy organisations and in some cases local area co-ordination teams.

The full list of data items requested by the LDSS team is listed in the LDSS data guidance, issued on an annual basis. The latest guidance can be found here:

https://www.scld.org.uk/wp-content/uploads/2018/04/Guidance-Notes-2018.pdf Many of the items are collected as a matter of course by local authorities. Management Information Systems vary from local authority to local authority. Some local authorities compile data through the use of CareFirst and others through SWIFT. Other local authorities use specially designed versions of Microsoft Access.

# Name of the organisation responsible for the original data source

Aberdeen City Council Aberdeenshire Council Angus Council Argyll and Bute Council City of Edinburgh Council Comhairle na h-Eilean Siar Clackmannanshire Council **Dumfries and Galloway Council Dundee City Council** East Ayrshire Council East Dunbartonshire Council East Lothian Council East Renfrewshire Council Falkirk Council Fife Council Glasgow City Council **Highland Council** Inverclyde Council Midlothian Council Moray Council North Ayrshire Council North Lanarkshire Council Orkney Islands Council Perth and Kinross Council Renfrewshire Council Scottish Borders Council Shetland Islands Council South Ayrshire Council South Lanarkshire Council Stirling Council West Dunbartonshire Council West Lothian Council

## • The purpose of the administrative/management system/source

Social work data: needs assessment, service delivery, operational monitoring, resource allocation, performance measurement and other purposes.

# • Unit of inquiry (for example, claimants, taxpayers, households, accidents)

Individual adults with learning disabilities as defined in 'The keys to life.'

For the purposes of LDSS, an adult is defined as:

- 16 and 17 year olds with learning disabilities and/or on the autism spectrum who are not in full-time school education
- A person with learning disabilities and/or on the autism spectrum aged 18 or over who are known to local authorities.

All adults who match these criteria and who are known to the local authority regardless of the services they are currently receiving (if any) should be included in the return.

For the purposes of this collection, a learning disability is defined as:

A learning disability is a significant lifelong condition which is present prior to the age of eighteen and which has a significant effect on a person's development. People with a learning disability will need more support than their peers to:

- Understand new and/or complex information,
- Learn new skills, and,
- To lead independent lives.

Learning disability does not include specific learning difficulties such as dyslexia. An acquired brain injury which occurs at age eighteen or over would also not be considered as a learning disability. Where a person has a learning disability and an autism spectrum diagnosis, they should be recorded as having a learning disability under this item and an AS diagnosis under the "Autism Spectrum Diagnosis" item. Where a person has an AS diagnosis but no associated learning disability, this should be recorded as none for this item.

# Intended coverage of administrative/management system/source

It is intended that the LDSS data collection captures information on all adults with learning disabilities known to local authority services.

# • Completeness that is actual coverage (for example, take-up rate)

Management Information Systems will typically collect information on people with learning disabilities who are receiving a funded service from local authorities. They may fail to capture individuals with learning disabilities who are not receiving a funded service and thus these individuals may need to be included in the LDSS return by referencing other local authority departments, further education organisations.

Furthermore, local authorities may not collect all data items on all individuals.

LDSS provides a table outlining the completeness of the collection on any given data item within the Statistics Release.

## Geographical coverage of the statistical product

Data are collected from all 32 local authorities. This provides both a local authority and a national (Scottish) picture.

## • Lowest level of geographical coverage

Local authority area.

# • Extent to which statistical end-producers can influence the system

The statistical end-producer team have no opportunity to influence the system. The data originates in local authority systems and is uploaded to the LDSS Team via an off-site secure upload. Once checked, the data are returned to the data providers before analysis to ensure accuracy of the data in its final form. Further, any presentational or material changes made to any stage of the process is data provider led via the Data Group comprising all 32 local authorities.

### • Data definitions used

Data definitions across 274 items were developed in 2009 in conjunction with Scottish Government and local authorities.

The development of data standards occurred as detailed below:

First version produced by the Social Care Data Standards Project 1. Version produced following review by the eSAY team, project

partners and the Social Care Data Standards Project 2 (SCDS2).

Revised version following review by eSAY project partners.

Version released for national consultation.

Version incorporating views from the national consultation. Released for further round of consultation.

Version released to stakeholders following the second round of national consultation.

First full national release.

Revised version to bring core items into line with changes in the Generic Core Data Standards.

Core items updated:

Person current gender, date of birth, first language, interpretation assistance, preferred communication method, accommodation type, household composition, tenure type, dwelling type and employment status.

Non-core items updated:

Area code, communicative understanding, lives with family carer, education and day opportunities.

Revised version following consultation. All generic core items fully compliant with the Social Care Data Standards Manual V2.0.

Ethnic group has been modified to include only top level codes.

Autistic Features replaced with Autism Assessment Status.

Lives with family carer – code 02 changed to 00.

Communicative Understanding has been updated.

Interpretive assistance indicator, codes renumbered to reflect the generic core.

Only 20 core data items are collected from the 274 definitions agreed in 2009.

The 20 items collected for LDSS 2018 are:

Person Service Status ID number Learning disability Autism spectrum diagnosis Area code/Health board code Person current gender Person date of birth Ethnic group Accommodation type Lives with family carer Number of people with a learning disability living in the same accommodation Advocacy Personal life plan Further education **Employment opportunities** Day centre attendance Local Area Coordination Postcode CHI Social Care ID Number

Full definitions and coding framework for each item are available in the Data Guidance for 2018:

https://www.scld.org.uk/wp-content/uploads/2018/04/Guidance-Notes-2018.pdf

#### • The data collection process

#### Periodicity/timing

Data are collected on an annual basis. The data collection year begins in April with a deadline for data submission of July; this year the deadline was August 17th 2018, though due to GDPR issues the collection was extended into October.

Data are cleaned and checked in the period August - September. Analysis takes place between October - November and the annual Statistical Release is published in December 2018.

## Validation procedures

The ProcXed system has in-built data validation checks that allows 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. Furthermore, the local authorities cannot submit data without it being approved by the SCLD team.

## Access arrangements for policy/operational/etc. purposes

Scottish Government policy colleagues are included in the pre-release access list for the LDSS statistics release to enable them to brief the minister on the contents of the release and prepare responses to any questions which may be asked.

## • Dissemination procedures (and publication procedures where appropriate)

Local authorities and the Scottish Government receive a pre-release version of the report 7 days before public release. This is sent by e-mail. On publication day, the report is sent to data suppliers, Scottish Government and any other parties who have previously consented to receiving the release by e-mail. The release is also made available on the homepage of the SCLD website http://www.scld.org.uk/ and on the publications page of the LDSS section of the SCLD website

https://www.scld.org.uk/what-we-do/population-statistics/

## Change process

## • Procedures for changing definitions, scope, etc

The LDSS Data Standards, and the codes extracted from it and used in the LDSS Guidance, are subject to the standard change control procedure for all social care data standards. Changes are most often suggested by the LDSS Team in response to data provider requests or feedback. Specific requests for changes can also be made to the LDSS team.

Changes are likely to be to the wording of the definition, recording guidance or codes. There are two types of change that can be made to a data standard:

A material change which affects the way that data are recorded – for example, where a new code value is added to a data item codeset, or the coverage of a descriptive term is expanded to include entities or processes which thus become new subjects of data recording.

A presentational change, where a standard is reworded or reshaped for clarification purposes, which doesn't materially affect the way that data are recorded.

Under the change control procedure, potential changes to the codes and data items will be discussed and agreed with data providers via data group meetings and discreet surveys prior to them coming into effect.

The changes made to the data items will be made clear in all published documents.

## The subsequent statistical production process

## Validation procedures

SCLD receive the data from the ScotXed team via a secure download from the ProcXed system. The SCLD team then separate identifying information (postcodes and date of birth) from the rest of the data. Both are then stored separately on a secure server, which can be accessed only by the statistical team, all of whom ensure adherence to General Data Protection Regulations and UKSA Code of Practice confidentiality principles to maintain data security.

Data is again checked for errors and consistency such as coding errors in the first instance. A number of data checks are employed on received datasets to ensure the data contained within is as accurate as possible and all obvious errors, for example in data processing, are corrected.

This analysis forms the basis for the content of the annual statistical release. The statistical team undertake all data analysis in Stata and Microsoft Excel.

## Quality assessment

Statistics produced by LDSS are assessed using guidelines based on the European Statistical System's six dimensions of quality. This document can be found here:

https://www2.gov.scot/Topics/Statistics/About/QualityCPS

Further, the LDSS data are derived directly from local authority administration systems. Local authorities regularly carry out internal audits on their data systems with the aims of ensuring accuracy and improving data quality. These checks may also take place to reflect changes in local policies and performances. Local authorities are likely to be interested in the relevance of their data to local policies, the accuracy of the data and the timeliness of its publication.

The data collected by LDSS is included in these local authority wide audits and the LDSS team are made aware of these being carried out and their potential to impact on data quality improvement where appropriate. These audits are carried out over and above any individual checks local authorities may carry out on the specific data they provide to LDSS. Both authority wide audits and specific LDSS data checks at a local level can result in changes to the data submitted to LDSS, usually as the result of a quality improvement exercise where a data source has been 'cleaned' and checked for accuracy. Where inaccuracies are found, these would be corrected and any resulting impact on the LDSS data would be clearly stated within the statistical publication with a full explanation as to the extent and cause of the impact. In this way, LDSS functions as a method of highlighting incorrect and/or out of date information which requires to be changed within the administrative source to ensure accurate data are then fed through the LDSS collection process.

To ensure the commitment to quality is continued beyond the initial data collection and upload phase, the LDSS team carry out their own data checks once data has been submitted and before it is confirmed for analysis. Specifically, the data are checked for percentage changes from the previous year, the presence of outliers, discrepancies and inconsistencies in order to determine where fluctuations in the numbers recorded differ significantly from the previous year and require the inclusion of an explanation as to why. Where these issues, or other issues which may have an impact on data quality, are identified, communications with the local authority data providers are opened to put in place a method of rectifying and/or detailing the effects they may have on the published data.

Local authorities are given the opportunity to check their data collection process at a local level to correct any errors which may have occurred during the aggregation of data into the LDSS upload. Where a discrepancy is not as a result of data input error, local authorities are requested to check the original data source for accuracy. Where the data are found to be correct, explanations to be included in the published statistical release are sought from local authority data providers to explain significant increases/decreases, outliers and inconsistencies observed in the data. Actions taken tend to be at a local level. Where the issue identified is one which could affect a number of authorities, all affected data submissions are checked and information would be shared with the local authority data suppliers as to the issue identified. On occasion, data can be found to be inaccurate and the problem has been with the data collection process itself, for example a misinterpretation of LDSS codes or processes. In these instances, work focuses on amending any collection issues for future data collections and the impact it has had on the current data would be made explicit in the statistical release.

## • Periodicity of release

The LDSS Statistics Release is published annually in December.

#### • Potential impact of changes to the administrative/ management system on the statistics

Local authority data suppliers are required to collate data items on people with learning disabilities in accordance with the Data Guidance issued by the LDSS project. This means that changes to the administrative or management systems should not disproportionately impact upon the statistics.

However, it is the case that some local authority social work departments do not record people with learning disabilities for whom they do not provide a service. LDSS is clear that records should be provided on:

- 16 and 17 year olds with learning disabilities and/or on the autism spectrum who are not in full time education, and;
- All adults with learning and/or on the autism spectrum aged or over,

who are known to local authorities, regardless of whether they are receiving a service.

This can result in local authorities having to seek data from other internal and external organisations to provide a complete return. Where local authorities do not invest resources in checking for data from other internal or external sources, this can lead to an under-estimate in the number of people with learning disabilities within a local authority area.

## • Procedures for mitigating such discontinuities

Local authorities are provided with clear guidance, on which they have been consulted, on an annual basis.

Local authorities are invited to complete a commentary form when they submit the data to describe the process and comment upon any difficulties. This helps the LDSS team to understand what data has been provided and where they may be discrepancies. This information is reported in the annual LDSS Statistics Release, so that data users are aware of what data has been collected by local authorities and of any caution needed in interpreting the data.

## • The impact of potential inaccuracy

Despite the wide data quality audits and checks carried out at both a local and a national level, it remains possible that inaccuracies could be present in the LDSS data outputs, either as a result of an inherent inaccuracy in the data source or as a collection or processing error which has not been identified. We strive to engage with users of our statistics and have recently undertaken an exercise to identify, as far as is possible, who our users are beyond those we are in regular contact with. The benefits of this task were multiple. Understanding our users and their needs allows an awareness of the impact any inaccuracies, inherent or otherwise, would have on different user groups.

To date, the LDSS statistics are primarily used to inform local authority service planning, to provide an evidence base for research and funding applications, comparative data analysis, to evidence service use and value, policy responses and internal reporting. Any inaccuracies found on the data sources utilised and, subsequently, in the data published, would obviously have an impact on the uses and outputs above. However, the seriousness of any level of inaccuracy found within LDSS is likely to be limited and fairly contained in comparison to other national statistical collections in Scotland, as LDSS is not used to inform any other statistical product.

Owing to the number of data providers (32) and the individualism of the administrative information management systems and data sources from

which they extract LDSS data, it is highly likely any inaccuracy would be specific to a very small number, if not an individual, local authority area. Further, the routine nature of local authority data audits and of the LDSS specific annual checks at a local and a national level, the data handled is often subject to interrogation at source and it is highly unlikely any inaccuracies found would span large time periods or variables.

It is much more likely, as has been the case in previous years, inaccuracies identified are localised within areas and/or variables. In all cases, the LDSS team remain committed to presenting the statistics in a clear and transparent manner and all inaccuracies identified would be made explicit, and the resulting action/amendment communicated as soon as is practically possible.