



Consultation Response

Data Strategy for Health and Social Care

The Scottish Commission for
People with Learning Disabilities
August 2022



About SCLD

The Scottish Commission for People with Learning Disabilities (SCLD) is an independent charitable organisation and partner to the Scottish Government in the delivery of Scotland's learning disability strategy, *The keys to life* and the Towards Transformation delivery plan.

SCLD is committed to creating an environment in Scotland in which systems and culture are changed to ensure people with learning disabilities have opportunities and are empowered to live the life they want in line with existing human rights conventions. SCLD believes that the discrimination and barriers faced by people with learning disabilities and other disabled people are not inevitable. These barriers stop people with learning disabilities and other disabled people being included in society and participating on an equal basis.

Introduction

SCLD welcomes the opportunity to respond to the Scottish Government consultation on the Data Strategy for Health and Social Care. In the following, SCLD outlines the main points put across to us in a recent engagement event with people with learning disabilities. These points relate in particular to empowering people, the importance of data governance and concerns around digital exclusion.

SCLD also provides further comments relating to data standards and interoperability within the current health and social care data landscape. These are based primarily on our experience working with local authorities to gather and publish information about people with learning disabilities through the annual Learning Disability Statistics Scotland (LDSS) publication,¹ as well as reflections from working in the area of health and social care data more generally.

SCLD believes that the collection of robust data on the experience of people with learning disabilities is vital in the promotion of equality and the protection of human rights within Scotland.

SCLD believes that the Data Strategy for Health and Social Care provides an opportunity to make people with learning disabilities visible within health and social care data, which will allow for planning, implementation and monitoring of services and interventions that can empower people to live their best lives. However, this can only be done with significant investment in data infrastructure and analytical expertise.

It is pivotal to ensure the interconnectedness of this strategy with the Equalities Evidence Strategy, the National Care Service (Scotland) Bill, as well as other strategies and legislation aiming to empower people with learning disabilities, such

¹ [Population statistics - SCLD](#)

as the new Human Rights Bill, and the Learning Disability, Autism and Neurodiversity Bill.

Background Engagement with People with Learning Disabilities

In March 2022, SCLD, alongside the Scottish Government, convened a focus group of people with learning disabilities to discuss the Data Strategy for Health and Social Care and gather their views.

Although these were captured by the Scottish Government at the time, it is worth reiterating a few of the main points in this submission.

- Participants felt frustrated at having to repeat themselves constantly, in particular about their support needs and medical conditions. They hoped that the data strategy might address this, by allowing data to be stored in a way that can be easily shared with those who need to see it.
- Equally important to participants was the need to ensure that their permission had been given to share this data, and that it was only shared with those who needed to see it.
- Participants felt more comfortable with the idea of their data being shared for helpful and non commercial purposes. However, they were clear that their permission should still be sought regardless of the purpose.
- Participants worried about those who were digitally excluded. They felt it was important for people to have the option to have everything explained by phone-call.

Learning from Learning Disability Statistics Scotland and the wider Social Care Data Landscape

Introduction

SCLD has long believed that robust data on the experience of people with learning disabilities, including how having a learning disability intersects with other protected characteristics, is absolutely vital in the promotion of equality and the protection of human rights. Without this data, we are unable to talk authoritatively about the population of people with learning disabilities, or plan and implement services and interventions that improve the lives of people with learning disabilities.

A recent report by the Fraser of Allander Institute highlighted the particular invisibility of people with learning disabilities within data collections in Scotland, and the difficulties this causes in terms of effective policy interventions:

“It is difficult, if not impossible, to effectively operationalise a policy if you have no idea how many people need to draw on support, nor do you know what their current situation is and therefore what assistance they actually require.”²

Pivotaly, lack of data significantly hampers our ability to measure human rights and equalities impacts across the board. This has never been demonstrated more clearly than during the Covid-19 pandemic, where it took more than 8 months to report on how many people with learning disabilities died from Covid-19.

It is acknowledged that adult social care data in general requires urgent transformation. In February 2020 the Office for Statistics Regulation published a

² [Fraser of Allander \(2021\)](#)

systemic review into adult social care statistics in Scotland.³ The report identified a number of issues that make it difficult to build a full picture of the state of adult social care in modern Scotland. These included gaps in data collection, resources weighted towards health data, inconsistencies in data definitions, poor data quality, delays in reporting and inaccessible data:

“There are gaps in the provision of statistics on social care – we don’t know how many people currently need social care and whether those needs are being met, how many people might need care in future, and we don’t know how well social care services achieve their goals of helping people to live independently and maintain a good quality of life.”⁴

Importantly, the report highlights the extent of the challenge involved in improving the underlying data:

“The biggest challenge – logistically, technically and financially – is improving the underlying data used to create social care statistics. This will involve improving the quality of existing data and identifying ways to capture new data to fill the many gaps that users have identified.”⁵

It is clear that the health and social care data strategy must be cognisant of these wider issues. It is also imperative however that any attempts to address these issues must not lose sight of populations who currently face huge inequalities across the board, including people with learning disabilities.

³ [Office for Statistics Regulation \(2020\)](#)

⁴ *Ibid, page 2*

⁵ *Ibid, page 4*

[Learning Disability Statistics Scotland - Background](#)

Learning Disability Statistics are collected as a result of the Scottish Government's [‘The same as you?’](#) review of services for people with learning disabilities, published in May 2000. The review proposed 29 recommendations for developing learning disability services and set out a programme for change, including recommendation 9, which stated that local authorities should keep local records of the number of adults with learning disabilities in the area and the services they use in order to plan services to meet their needs.

In 2001 the Scottish Government introduced an annual statistical return on adults with learning disabilities at both national and local authority level in order to monitor progress of ‘The same as you’ policy. Between 2001 and 2007 the Scottish Government collected the data on adults with learning disabilities based on aggregate totals. However, since 2008 SCLD has published an annual return on behalf of the Scottish Government. LDSS is one of the only National Statistics publications in relation to health and social care that is *not* currently published by one of the three bodies with primary responsibility for official statistics on social care in Scotland (the Scottish Government, Public Health Scotland and the Social Services Council.)

[Learning Disability Statistics Scotland – Merger with Wider Social Care Collection](#)

The collection and submission of this data is a significant resource burden for local authorities. At the heart of this is the fact that social care and support for people with learning disabilities is complex; taking social inclusion as its foundation and straddling a number of key policy areas as a result; including education, employment, accessing health, housing and leisure services.

This complexity has been demonstrated acutely over the past 6 years. SCLD has been working with Public Health Scotland and the Scottish Government since 2016

in attempt to merge LDSS within Public Health Scotland's social care data collection, in order to reduce provider burden as well as improve analyses through linkage to key health related data.

However, information governance, different systems of collection, reduction in data/analytic staff in local authorities as well as lack of expertise in learning disability in the wider health and social care data landscape have led to delays in this process. These delays mean that the latest LDSS publication relates to data that was collected in 2018/19, and as such, is not a useful set of statistics for policy or service planning.

Moving Forward

It is crucial that all are taken into consideration within the data strategy for health and social care. Taking action to significantly improve data that allows for the disaggregation of equalities information, including whether a person has a learning disability, is critical to improving decision-making, accountability and, importantly, people's lives.

It is also important to recognise that, whilst there may be common issues across the whole of the social care sector; and therefore, commonalities in the types of data that would be useful to collect; the experience of people with learning disabilities are very different from others utilising the social care system, particularly elderly people.

If designed and implemented carefully, the new health and social care record proposed in the National Care Service Bill could prove a useful tool, not only for empowering people with learning disabilities to make decisions about their care and support, but also as a way to link to data about other important aspects of people's lives, such as education, employment and socio economic status.

Getting this right will require significant investment in data infrastructure and workforce in social care statistics, and a detailed understanding of the complexity of social care and support for people with learning disabilities.

While it is pivotal that we put this in place as a matter of urgency, it is equally important that we ensure that the right data is collected in the right way, with human rights and equalities embedded.

This will require effective engagement with people who utilise services, including people with learning disabilities, and those that work with and for them.



Ruth Callander
Evidence and Data Adviser
Scottish Commission for People with Learning Disabilities
Ruth.C@scl.d.co.uk

Contact us

Website: www.sclld.org.uk

Twitter: [@SCLDNews](https://twitter.com/SCLDNews)

Facebook: [@ScotCommission](https://www.facebook.com/ScotCommission)

Instagram: [@sclldnews](https://www.instagram.com/sclldnews)

To find out more about SCLD and the work we do, please visit: www.sclld.org.uk

The Scottish Commission for Learning Disability
Suite 5.2
Stock Exchange Court
77 Nelson Mandela Place
Glasgow
G2 1QY

