



Consultation Response

Equality Evidence Strategy 2023-25: Consultation

The Scottish Commission for
People with Learning Disabilities
October 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

The Scottish Commission for People with Learning Disabilities (SCLD) welcomes the opportunity to respond to the Scottish Government's Equalities Data Strategy 2023-25 Consultation.

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.

In the following, SCLD provides comment on the questions that are most relevant to our work with people with learning disabilities in Scotland. Our comments are informed by our experience working with people with learning disabilities and their carers/supporters, as well as our experience as a third sector body with responsibility for the annual Learning Disability Statistics Scotland publication.¹

SCLD believes that the Equalities Evidence strategy provides an opportunity to make people with learning disabilities visible within data – in particular 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 also pivotal to ensure the interconnectedness of this strategy with the Data Strategy for Health and Social Care, any review of the Core and Harmonised questions, the National Care Service (Scotland) Bill, as well as other strategies and legislation aiming to empower people with learning disabilities, such as the new Human Rights Bill, and the Learning Disability, Autism and Neurodiversity Bill.

¹ [Population statistics - SCLD](#)

Section 1: Vision

Do you think the Scottish Government should revise the vision developed in 2017?

SCLD is happy with the proposed vision and does not think it needs revised.

Section 2: Proposed Actions

To what extent do you think that the proposed actions would adequately deliver on our ambition for a robust and wide-ranging equality evidence base?

The proposed actions are only likely to partially deliver on the ambition for a robust, wide-ranging equality evidence base. SCLD believes that until disability data is collected systematically in such a way as to allow the disaggregation of people with learning disabilities – and in turn, other impairments – then policy and service delivery decisions will inevitably fail to take the needs of people with learning disabilities into account.

Are there any proposed actions that you think should be revised? Please tell us which actions you think should be revised and how.

In relation to the Health and Social Care Actions (19-24), while SCLD recognises that these actions are ambitious and to be welcomed, there are more fundamental issues to be addressed, as highlighted by the Glasgow Centre for Population Health in its own submission to this consultation.² In summary, various parts of the NHS do not collect equalities data, either at all, or in ways that can be utilised.

SCLD also believes that the lack of focus on any social care datasets is disappointing. It is assumed that this is due to the fact that the Scottish Government does not own/control any social care datasets.

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

² [Equality Evidence Strategy 2023-2025 GCPH response.pdf](#)

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

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

SCLD believes that significant investment in the SOURCE Social Care⁶ dataset, including investment in local systems that allow for the capture of equalities data (including impairment type) is pivotal, and should be reflected in this strategy.

Are there any additional improvement actions that you think should be considered that are achievable within the 2023-25 time period?

SCLD understands that the content of the Core Questions are due to be reviewed. It is our belief that the most appropriate way to gather robust equalities information, including information about a person’s learning disability status, is for all the major population surveys, to include the ‘Disability or Long Term Health Condition’ core question, as well as the more detailed follow up question related to impairments.

⁴ *Ibid*, page 2

⁵ *Ibid*, page 4

⁶ [Insights in social care: statistics for Scotland - Support provided or funded by health and social care partnerships in Scotland 2019/20 - 2020/21 - Insights in social care: statistics for Scotland - Publications - Public Health Scotland](#)

We suggest that the follow up question be redesigned in such a way that would allow for the disaggregation of learning disability – and in turn other impairments - by following the disability and long term health condition question from the 2022 Census, as shown:

18 Do you have any of the following, which have lasted, or are expected to last, at least 12 months?
 ◆ Tick **all** that apply

Deafness or partial hearing loss

Blindness or partial sight loss

Full or partial loss of voice or difficulty speaking (a condition that requires you to use equipment to speak)

Learning disability (a condition that you have had since childhood that affects the way you learn, understand information and communicate)

Learning difficulty (a specific learning condition that affects the way you learn and process information)

Developmental disorder (a condition that you have had since childhood which affects motor, cognitive, social and emotional skills, and speech and language)

Physical disability (a condition that substantially limits one or more basic physical activities such as walking, climbing stairs, lifting or carrying)

Mental health condition (a condition that affects your emotional, physical and mental wellbeing)

Long-term illness, disease or condition (a condition, not listed above, that you may have for life, which may be managed with treatment or medication)

Other condition, please write in:

No condition

In the longer term, it will be important to ensure consistency in the way that equalities information is captured across all data collections, from local management information systems to population surveys.

Section 3: Use of equality evidence

Do you face any barriers to using equality evidence?

Currently there are many gaps in the sort of equalities data and evidence SCLD would like to be able to utilise in order to understand the experience of people with learning disabilities – including those facing multiple layers of discrimination due to intersecting protected characteristics.

In general, we are simply not able to do this, as learning disability data is not disaggregated in the vast majority of data sources. Even where such data *may* be collected, it is not made available by public organisations, with data protection concerns, often used as an excuse for not making equalities information more publicly available.

This lack of data restricts evidence-based policy making, disrupts project planning, and impedes project delivery.

While collecting information from people with lived experience of learning disability is a core activity of SCLD, this does not allow us to understand how people's experiences might be changing over time. The same is true of academic studies which are another source of equalities data that SCLD utilises. It is also worth noting, that as a third sector organisation, SCLD works on a limited budget and so does not have unlimited access to academic journals, or indeed unlimited resources to undertake primary research.

A recent example of some of the routine barriers faced comes from attempts to undertake an Equalities Impact Assessment (EQIA) of the Scottish Government's *Towards Transformation*⁷ plan, published in 2021. The intention of the EQIA was to identify areas of multiple discrimination, and understand how *Towards Transformation* might help or hinder equality of opportunity for different groups. However, within this process it became clear that it was not possible to look in any detail at the experiences of people with the majority of the protected characteristics for numerous reasons:

- Lack of systematically collected equalities data;

⁷ [Learning/intellectual disability and autism: transformation plan - gov.scot \(www.gov.scot\)](https://www.gov.scot/learning-intellectual-disability-and-autism-transformation-plan)

- Lack of disaggregation of learning disability status within data;
- Lack of academic studies looking at the experience of people with learning disabilities and other protected characteristics;
- People with learning disabilities, and organisations working with people with learning disabilities are tired of telling their stories repeatedly when nothing changes for them in the short term.

SCLD thanks the Scottish Government for the opportunity to respond to this consultation.



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