Position Statement

Building back with better data:

The importance of collecting and recording appropriate data on people with learning disabilities in Scotland

The Scottish Commission for People with Learning Disabilities

October 2020 (2022 Update)

Background

Why is routine data collection required?

The collection of robust data on the experience of people with learning disabilities, including how having a learning disability intersects with other protected characteristics, is vital in the promotion of equality and the protection of human rights within Scotland.

Without sufficiently disaggregated and robust national data, it is difficult to talk authoritatively about the population of people with learning disabilities, or plan and implement services and interventions that empower people with learning disabilities to live their best lives.

Critically, lack of data significantly hampers the ability to measure human rights and equalities impacts across the board.

United Nations Expectations

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) which the UK ratified in 2007, is fundamental to the realisation of rights and the delivery of duties by Governments.

Article 31 of the UNCRPD makes it clear that gathering data and statistics, analysing and applying that knowledge to the design and delivery of public services is key to the realisation of rights, equally.

Article 31 stipulates that governments *"collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention"*, including appropriate disaggregation.[1]

Article 33 also requires the co-ordinated monitoring of compliance including the involvement of civil society, and in particular persons with disabilities and their representative organisations. In promoting, protecting and monitoring the implementation of the UNCRPD, the participation of people with learning disabilities and data gathering are key elements.

Scottish Policy Expectations

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[1] More information is available at: https://keystolife.info/wp-content/uploads/2019/03/Keys-To-Life-Implementation-Framework.pdf

Within Scotland, there are a number of policy provisions in place that recognise the need for robust data:

- *The keys to life* strategy highlighted the need for people with learning disabilities to be visible within routinely collected health data in order to understand need, make better health policy based on this understanding, and demonstrate improved outcomes.[2]

- 'A Fairer Scotland for Disabled People'**[3]**, which is the national delivery plan for the UNCRPD to 2021, includes a commitment to gather data on services which supports the delivery of independent living outcomes (page 15).

- '*The keys to life:* implementation framework and priorities 2019-2021[4] recognises the pivotal role of robust data and the work by Public Health Scotland and SCLD to incorporate Learning Disability Statistics Scotland (LDSS) into routinely collected health and social care data.

Identified Gaps

Despite this, the United Nations Committee on the Rights of Persons with Disabilities directly addressed the UK's lack of statistics and data across the life course for persons with disabilities in 2017:

> *"64. The Committee is concerned at the lack of a unified data-collection system and indicators across the State party concerning the situation of persons with disabilities. It notes the limited collection of disaggregated data in surveys and censuses on the general population.*
>
> *65. The Committee recommends that the State party, in line with Sustainable Development Goal 17, significantly increase the availability of high-quality, timely and reliable data disaggregated by, among others, income, sex, age, gender, race, ethnic origin, migratory, asylum-seeking and refugee status, disability, geographic location and other characteristics relevant in national contexts, including in all general population surveys and censuses."*[5]

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[2] See specifically Recommendation 9 (page 26) https://keystolife.info/wp-content/uploads/2019/03/the-keys-to-life-full-version.pdf

[3] More information is available at http://www.gov.scot/Publications/2016/12/3778

[4] More information is available at: https://keystolife.info/wp-content/uploads/2019/03/Keys-To-Life-Implementation-Framework.pdf[5] UN Committee of Persons with Disabilities, 2017 (CRPD/C/GBR/CO/1)

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SCLD is aware that the Scottish Government is working to align its National Performance Framework to UN Sustainable Development Goals, aiming to realise human rights for all and making a commitment to *"…increase significantly the availability of high-quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts."*[6]

However, it is clear that there remains significant challenges around the collection of robust disaggregated data for people with learning disabilities.

Recent Concerns

The Covid-19 crisis has brought into particularly sharp focus Scotland's lack of data in relation to people with learning disabilities. From SCLD's perspective, the most revealing aspect of this has been the enormous challenge in Scotland to report on how many people with learning disabilities have died from Covid-19.

Furthermore, the UN Committee on the Rights of Person with Disabilities has said the COVID -19 pandemic has 'revealed that the Convention on the Rights of Persons with Disabilities (CRPD) has not been comprehensively implemented by States Parties. It has starkly exposed the heightened vulnerability and risks to persons with disabilities that is underpinned by entrenched discrimination and inequality'.

In England, the death rates of people with learning disabilities from Covid-19 have been reported from two sources; a targeted piece of work by the Office for National Statistics using information on care home deaths reported to the Care Quality Commission,[7] and a weekly update of Covid-19 deaths reported to the Learning Disability Mortality Review (LeDeR).[8]

The Scottish Learning Disability Observatory (SLDO) undertook a study uncover these figures for Scotland, but this was not completed until March 2021. The fact that this required a complex linkage of National Records of Scotland (NRS) and NHS controlled datasets resulted in a significant delay in understanding how the crisis was impacting people with learning disabilities in Scotland.

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[6] https://nationalperformance.gov.scot/sustainable-development-goals

[7] More information here: https://www.cqc.org.uk/news/stories/cqc-publishes-data-deaths-people-learning-disability

[8] More information here: https://www.england.nhs.uk/publication/covid-19-deaths-of-patients-with-a-learning-disability-notified-to-leder/

It is also important to note that the issue around lack of robust, disaggregated data in Scotland predates the Covid-19 crisis. Despite the above mentioned legislative and policy provisions, disaggregated data on the experience of people with learning disabilities in basic health data, as well as across social, economic and political life is difficult to obtain. In terms of intersectional impacts the data is even more sparse.

The most recent LeDeR report in England shows that people with learning disabilities from BAME groups died disproportionately at younger ages than white British people. Comparable data does not exist for Scotland.

Challenges

There are numerous reasons why this type of disaggregation is not straightforward. The definition of learning disability is broadly defined and can transcend or be confused with other common categorisations. Most often, learning disability is lost within pan-disability reporting, as the majority of data collection follows the 'core and harmonised questions'[9] approach.

This approach does not usually report on impairment type, and where this is collected it is done so in a way that does not allow the disaggregation of learning disability.

There is also a challenge to balance the need to disaggregate and monitor outcomes with individuals' right to data protection and privacy, as well as the freedom to self-identify.

However, these challenges should necessitate good data governance rather than serve as a barrier to the collection of appropriately disaggregated data.

Understanding Inequality

What we do know is that studies indicate that people with learning disabilities in Scotland continue to have high rates of premature mortality[10], experience restraint and seclusion

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[9] More information here: https://www2.gov.scot/Topics/Statistics/About/SurveyHarm/corealldownload

[10] *The keys to life* (2013)

practices[11], and face barriers to accessing appropriate health services[12], education[13], employment[14], relationships[15], and family lives[16].

The further availability of disaggregated data is therefore pivotal because it could inform on the extent of the inequality and discrimination people with learning disabilities experience and enable progress to be monitored against this.

Furthermore, better understanding of intersectional impacts would allow government and the wider public sector to appreciate multiple disadvantage and decision makers to consider more carefully what resources are allocated, how, and to whom.

Public Sector Equality Duty

Whilst the Public Sector Equality Duty does require Local Authorities to set measurable equality outcomes in Scotland, there is a lack of formal obligation on authorities to collect and monitor specified information. Without legal obligation and resources to collect this data, local authorities and other responsible bodies are likely to continue to make do with the current systems and processes, in which disaggregated data for people with learning disabilities is either incomplete or non-existent.

The Way Forward

In 'building forward differently' as Scotland responds to the challenges of Covid-19, it is imperative to take seriously the need to monitor and report on progress as well as on outcomes for groups who have been disproportionately impacted by the pandemic.

The Scottish Government and other public bodies in Scotland must ensure they collect and report appropriate data to enable the formulation and implementation of policies that give effect to the UNCRPD.

There is now a significant opportunity to establish structures that systematically record protected characteristics on disaggregated basis. This is essential if Scotland is to become the truly inclusive society it aspires to be.

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[11] PABSS & Challenging Behaviour Foundation (2019)

[12] SLDO (2018)

[13] ENABLE (2016) #IncludED in the Main?! 22 steps on the journey to inclusion for every pupil who has a learning disability

[14] McTeir et al (2016) Mapping the Employability Landscape for People with Learning Disabilities in Scotland

[15] Findings from the *'How's Life Survey?'* to be published in 2020

[16] SCLD (2018) Children's Rights: Consultation on incorporating the United Nations Convention on the Rights of the Child into our domestic law in Scotland

For further background and detailed information relating to disaggregated data collection please contact SCLD on data@scld.co.uk