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Scottish Commission for People with Learning Disabilities

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Dear Ed,

TEMPORARY SUSPENSION OF NATIONAL STATISTICS DESIGNATION FOR LEARNING DISABILITY STATISTICS SCOTLAND

I am writing to ask you to consider a temporary suspension of the National Statistics badging for the Learning Disability Statistics Scotland publication. Over the past three years, the Scottish Commission for People with Learning Disabilities (SCLD) and Public Health Scotland (PHS) (formerly Information Services Division) have been working to incorporate Learning Disability data within the established Social Care data collection. In previous years the Learning Disability data was collected separately.

The new arrangements are intended to provide richer and more useful statistics. They would facilitate linkage to health and social care data to enhance understanding of the social determinants of health for people with learning disabilities. They are intended to simplify the data collation effort at a local level. Due to the transfer of responsibility to PHS, they have however required a change to the national submission process previously used (Scottish Government's ProcXed system). This change in process has necessitated new Data Sharing Agreements be drawn up and put in place. This has not gone as smoothly as hoped and 11 partnerships have not yet signed these revised agreements.

The gap in signed agreements brings uncertainty as to when PHS can share the data with SCLD for analysis and publication – a Data Sharing Agreement is necessary for sharing to happen. Further, PHS has reviewed the completeness and quality of the data for the 24 partnerships which have made returns and report that the quality is generally not good. We have concluded that a joint exercise is necessary to resolve these issues with our data providers. This may further exacerbate the delay in assembling all the data for analysis and publication. Given these challenges, and our awareness that the National Statistics designation is intended to provide assurance to users of the quality, trustworthiness, and value of the release, it is our assessment that the most appropriate course of action would be to seek temporary de-designation for the 2021 release.

SCLD and PHS are very much committed to the success of LDSS. The COVID-19 pandemic has showed us that data can save lives. It has also shown us that people with learning disabilities are almost invisible within systematically collected data in Scotland - a situation we are trying to improve. To that end SCLD will continue to work with PHS, the Scottish Government and other stakeholders to ensure that the LDSS collection provides richer and more useful statistics moving forward.

Yours sincerely,

Ruth Callander, Evidence & Data Adviser, on behalf of Charlie McMillan, Chief Executive of SCLD

