

# Estimating the Future Number of People with Learning Disabilities Drawing on Adult Social Care Services in Scotland

A discussion paper based on replicated analysis for Scotland

February 2024

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## Background

The work in this discussion paper contributes to the Fraser of Allander Institute's [latest programme of research](#) looking at the lives of people with learning disabilities in Scotland.

As explained in [our report](#) from May 2023, our current programme of work on data looks at how we move from identifying issues towards building solutions.

Given the ongoing policy debate and legislative process around the creation of a National Care Service (NCS), we felt that the lack of evidence and analysis around those who draw on social care was an important place to build capacity.

This discussion paper attempts to replicate [analysis](#) previously conducted by the Centre for Disability Research (CeDR) at Lancaster University on behalf of Mencap for England. The [project](#) reported in 2012 and was funded by the National Institute for Health and Care Research (NIHR) School for Social Care Research.

The CeDR work has featured in projections of adult social care need in England produced by the Care Policy and Evaluation Centre (CPEC) at the London School of Economics and Political Science (LSE). We envisage that the new Scottish National Care Service will need projections of the number of people who draw on adult social care in Scotland in order to plan and operate effectively. The evidence for people with learning disabilities is a crucial part of the picture that we are keen is not overlooked.

It is important to note that there is thought to be considerable unmet need in the social care system. The NCS hopes, among other things, to reduce this unmet need, but as yet we have no understanding of how or when this will be achieved. This discussion paper focuses on projecting 'met' need - that is, under

current eligibility criteria, how many adults will draw on social care need in the future.

The process developed by CeDR was considered throughout our work, with an intention to follow the six-stage approach where possible and relevant to the framing of this initial analysis for Scotland.

When estimating future need for adult social care services for people with Learning Disabilities in England, CeDR applied their six-stage approach, in part to statistics sourced from National/Official data collections but also data sourced through other avenues. For instance, CeDR used data from the Information Centre for Health and Social Care and information extracted from the Sheffield, Merton, Sutton and Lambeth learning disability case registers to estimate the number and age profile of adults with learning disabilities who were using social care services.

CeDR also adopted a consultative approach to deriving estimates of the percentage of young people with learning disabilities who are likely to meet the criteria for social care services when they reach adulthood.

In this paper, we discuss the availability and suitability of Scotland level data and what this means for the results of our replicated analysis.

There are a number of areas where data improvement is needed before we can be confident of the figures that this analysis is producing are robust enough to use for planning purposes. This is why we have framed this as a 'discussion paper', rather than a 'report'. As well as areas where we have noted potential for improvement, there may also be other areas where stakeholders believe there are superior alternative methods.

In order to progress, we are likely to require input from other stakeholders with particular data expertise to achieve this, and we hope that publishing this discussion paper will help focus minds (and resources) on getting this analysis to a point where it can help shape policy decisions. We also hope that this paper helps to build understanding of the complexities in arriving at robust estimates, and that the process that follows helps to build consensus on the best way forward.

In addition to expressing our gratitude to the lead researchers from the original CeDR work - Professor Eric Emerson, presently of Lancaster University and Professor Chris Hatton, presently of Manchester Metropolitan University, we

would also like to extend our thanks to Public Health Scotland, Scottish Government's Education Analytical Services, Scottish Learning Disabilities Observatory, Scottish Commission for People with Learning Disabilities, NHS Fife and the National Records of Scotland for their support so far and hope to continue to work with many of these stakeholders in the continuous improvement required to build robust projections.

## The Replication Process

As already discussed, we have not considered unmet need in this initial analysis for Scotland. This work is therefore framed slightly differently from the CeDR work, with a focus on forecasting the numbers drawing on adult social care as opposed to estimating future 'need' for social care services.

We have however broadly followed the six stages which underpin the process of estimating future need in England (based on the work led by Professor Eric Emerson and Professor Chris Hatton).

### **1. Identifying children with additional support needs (ASN) associated with learning disability in Scotland**

This stage utilises data collected through Scotland's annual pupil census to determine administrative prevalence estimates for relevant categories of ASN.

### **2. Adjusting for child mortality**

Estimating the number of children with learning disabilities in Scotland who would reach the adult services age between 2022 and 2040. This required taking account of cohort attrition as a result of child mortality.

### **3. Estimating the number of young people who are likely to become users of adult social care services**

Deriving an estimate of the percentage of children with learning disabilities who are likely to become new entrants to social care services when they reach adulthood.

### **4. Estimating the number of adults with learning disabilities using adult social care services in Scotland**

Estimating the current number and age profile of adults with learning disabilities who are using social care services in Scotland from the Insights in social care: statistics for Scotland (support provided or funded by health and social care partnerships in Scotland).

### **5. Estimating attrition among current users of adult social care services**

Adjusting the cohort of current adult service users for the expected effects of mortality between 2022-2040.

## **6. Results - Estimating net changes in projected adult user population**

Net changes in the population of people with learning disabilities who use adult social care services between 2022-2040 are estimated by combining estimates of inflows from children's services with estimates of attrition in the cohort of current service users.

### **Stage 1: Identifying children with additional support needs (ASN) associated with learning disability in Scotland**

This stage utilised the data collected through Scotland's annual pupil census. These statistics are published each year by the Scottish Government. The published data on reasons for support for pupils with ASN did not provide the necessary detail by both age and sex. This data was therefore requested directly from the Scottish Government. Once received, we used the 2021 data as our starting point, with a focus on pupils aged between five and 15. This is because we refer to adult social care services in this work as being from the age of 16 and above.

The categories of ASN data collected through the pupil census in Scotland differs to England where they use the term Special Educational Needs (SEN). The pupil census in Scotland collects data on reasons of support which includes categories such as Learning Disability, Other Specific Learning Difficulty, Moderate Learning Difficulty and Autistic Spectrum Disorder. Pupils with more than one reason for support appear multiple times in the data. After much consideration we decided to focus on the cohort of pupils recorded as having a Learning Disability as a reason for support, for this analysis. This could be easily adjusted if we decided at a later point to broaden the analysis. For example, if we also wanted to include pupils recorded as having Autistic Spectrum Disorder as a reason of support. However, including multiple categories would mean that we could no longer refer to the cohort as unique pupils as some pupils may be included more than once.

The analysis undertaken by CeDR for England did consider multiple categories from their equivalent School Census exercise as this collects data on a different range of categories, compared to Scotland. The data collected on all children

attending school in England includes the following categories, a couple of which aren't covered in Scotland:

- MLD – Moderate learning difficulties
- SLD – Severe learning difficulties (not a category in Scotland's pupil census)
- PMLD – Profound and multiple learning difficulties (not a category in Scotland's pupil census)
- ASD – Autistic spectrum disorder

This marks one of the first differences in the work previously carried out in England, compared to what is currently possible for Scotland.

The proportion of pupils from the 2021 pupil census in Scotland by single year of age (between 5-15), with a learning disability recorded as a reason for additional support was calculated. This was done separately for both male and female pupils. These percentages were then applied to the equivalent population projections up to the year 2040, using data published by the National Records of Scotland. This resulted in the identification of 10,499 children with learning disabilities between the ages 5-15 in Scotland in 2021. This drops to 8,329 by 2040 which reflects the projected overall population decline over the next twenty years.

## **Stage 2: Adjusting for child mortality**

The second stage of this work involved estimating the number of children with a learning disability in Scotland who would reach 15 years of age between 2022 and 2040. To be able to estimate these numbers we were required to inform an adjustment to the cohort of children established in stage 1. This would take account for cohort attrition as a result of child mortality between the child's current age and age 15.

In the model for England, CeDR estimate that mortality rates among children with MLD would be 50 per cent higher than those observed among children in the general population of a similar age and gender. For children with SLD and children with Autistic Spectrum Disorder (ASD) and learning disabilities they estimated mortality rates based on information extracted from the Sheffield Learning Disability Case Register on child mortality over a period of ten years.

For children with PMLD they estimated annual mortality rates to be 50% higher than the rates estimated for children with SLD.

The estimates used in the CeDR research on a per year per 1,000 children basis for England were:

- MLD age 5-9 (0.17), age 10-14 (0.20), age 15-18 (0.56)
- SLD and ASD (7.40)
- PMLD (11.10)

After exploring different options for informing cohort attrition in Scotland and in the absence of case register data, which was available to CeDR, we decided to inform our analysis on a record linkage national cohort study. The [research](#), first published in 2022<sup>1</sup> investigates mortality rates and associated factors by considering individual record-linked data between Scotland's 2011 Census and 9.5 years of National Records for Scotland death certification data. The results estimate there to be 388 deaths per 100,000 for children and young people aged 5-24 with intellectual disabilities.

Employing this mortality estimate predicted an average of 36 deaths per year among the cohort of children with learning disabilities in Scotland between 2022 and 2040.

Whilst we applied this assumption to our work, we do appreciate that this finding relates to an age group which extends beyond the cohort we are considering. This assumption could therefore be strengthened if mortality rate data which is not only more age specific but is also gender specific becomes available, either through future research, or access to detailed datasets utilised as part of existing research. The collection of data for the different severity categories (MLD/SLD/PMLD) from school age in Scotland could have also had the potential to yield further insight into mortality through current longitudinal studies.

### **Stage 3: Estimating the number of young people who are likely to become users of adult social care services**

This stage of the process sees another departure from how the work was informed for England. Not all young people with learning disabilities will

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<sup>1</sup> Hughes-McCormack LA, Rydzewska E, Cooper S-A, et al. Rates, causes and predictors of all-cause and avoidable mortality in 163 686 children and young people with and without intellectual disabilities: a record linkage national cohort study. *BMJ Open* 2022;12:e061636. doi:10.1136/bmjopen-2022-061636

become users of adult social care services and there is no data available which provides the percentage of young people who become users of adult social care services. Therefore, a consultative approach was adopted in England to derive estimates. Factors including the likelihood to meet differing levels of eligibility for adult social care and rationing of access to those services by the eligibility criteria at that time in England were considered as part of the consultation.

The approach in England involved asking a range of expert organisations to provide their best estimate of the percentage of young people with MLD, SLD, PMLD, ASD and learning disabilities who, in their opinion, would meet the criteria for critical, substantial, moderate and low need. From this data, CeDR produced upper, middle and lower estimates of assessed level of eligible need by SEN associated with learning disabilities. These estimates were then sense checked with the same set of expert organisations.

Through contact with a senior expert within Learning Disability Services in the NHS in Scotland we also attempted to undertake a consultative approach to derive Scotland specific estimates. This was achieved in England but we do know it took some considerable effort to recruit suitable organisations. Whilst we designed a data collection template which we felt would have been simpler and a higher level ask compared to the level of detail collected in England, to date, we have had little response from Health Boards. We therefore haven't yet yielded sufficient data through this approach and whilst we consider other consultative avenues, we've applied an alternative option for now.

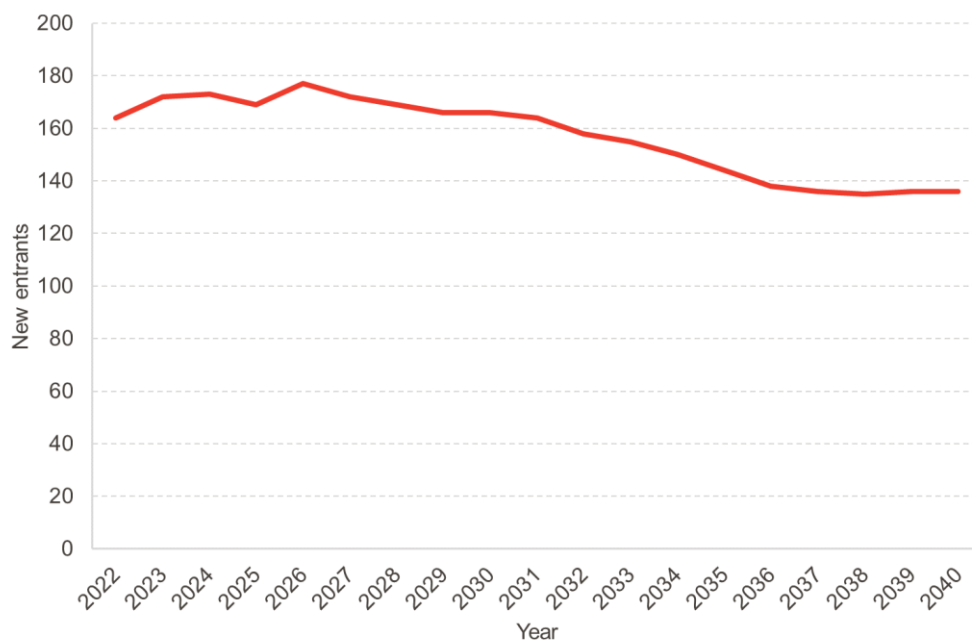
The option we decided to follow was a fairly crude method of comparing data for those aged 15 with learning disabilities in the pupil census with those aged 16 (now deemed adults in our analysis) with a learning disability receiving support which is provided or funded by Health and Social Care partnerships (HSCPs) in Scotland. The data on support for 16 year olds being sourced from the [Insights in social care: statistics for Scotland](#) and for a single year of age, provided directly from Public Health Scotland who are responsible for these statistics.

By comparing the relevant data on 15- and 16-year-olds from these two data sources this meant we were able to calculate a percentage estimate of the proportion of 15-year-olds with learning disabilities who become users of social care services when they reach adulthood (i.e. when they become 16). Due to data availability, we were only able to calculate and consider this percentage for the time period 2019–2021, where it has steadily increased from 4.2% in 2019



to 12.1% by 2021. As we go on to mention in step 4, this increase could potentially be Covid-19 pandemic related. A rise in the number of 16-year-olds with learning disabilities who draw on social care service is part of an overall jump for the adult population between 2019/20 and 2020/21, as highlighted by figure 2.

**Figure 1: Estimated number of new entrants to adult social care services in Scotland (2022 to 2040)**



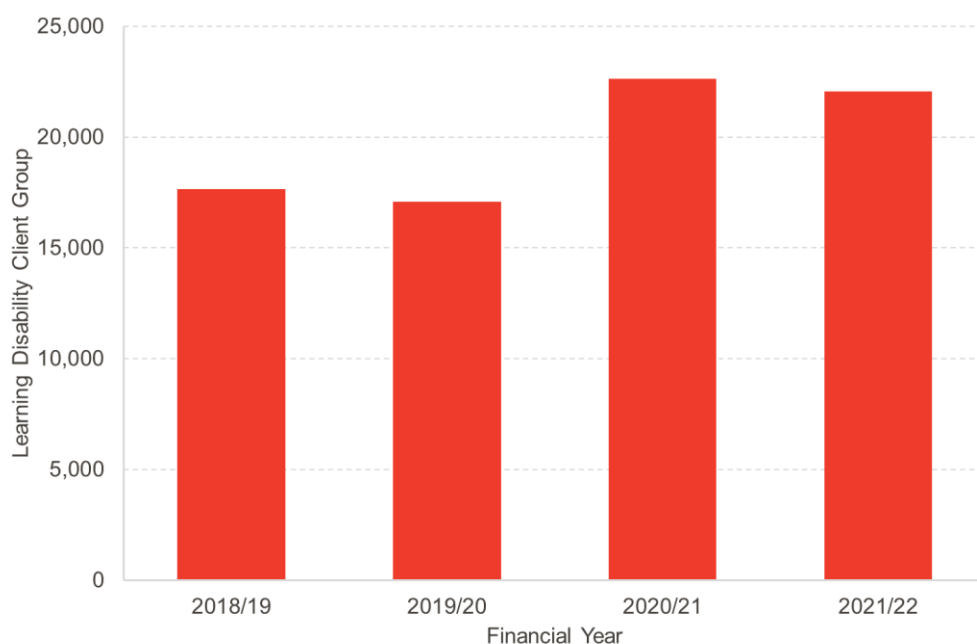
Whilst we will continue to track this emerging upwards trend, we have decided for now, to utilise the latest percentage for 2021 of 12.1%. This means we have applied the 12.1% consistently to the number of 15-year-olds with learning disabilities (adjusted for child mortality) as calculated in stage 2 between 2022 and 2040 to estimate the number of new entrants to adult social care services in Scotland. The results are presented in figure 1.

**Stage 4: Estimating the number of adults with learning disabilities using adult social care services in Scotland**

For this stage of the work, we again used data from Public Health Scotland’s Insights in Social Care Statistics for Scotland. This data refers to support provided or funded by health and social care partnerships in Scotland. Detailed data which broke down the numbers for the learning disability client group between 2017/18 and 2021/22 was requested and gratefully received from

PHS. This meant we were able to look at the data on an annual basis for 8 different age bands and at the HSCP level.

**Figure 2: Estimated number of adults (16+) with learning disabilities receiving support funded by health and social care partnerships in Scotland (2018/19 to 2021/2022)**



Having the detailed data was helpful as it meant we could apply adjustments to financial years where some HSCPs were unable to provide data. We did this based on data for years where those HSCPs were able to submit data. For example, we would roll forward a figure for a HSCP from the previous year to compensate for missing data.

The rise between 2019/20 and 2020/21 is a potentially interesting step change and could be a consequence of the Covid-19 pandemic. The younger age groups witnessed the biggest growth and some Local Authorities saw larger increases than others. After checking with PHS to see whether any supplementary information was available as part of the data submission process, we accept that there is no hard evidence to explain why this increase coincided with the pandemic.

It is important to note that like a lot of collections this data is likely to undercount social care clients with a learning disability who receive social care

services or support in Scotland in any given year. This is because the client group an individual is assigned to is determined by a Social Worker or Social Care Professional and is used as a means of grouping individuals with similar care needs. An individual can be assigned to more than one client group but only where the system being used to capture information can facilitate this, so there may be people with other conditions that are not being assigned to the learning disability care group as it is not deemed the primary reason for why they are drawing on social care support.

### Stage 5: Estimating attrition among current users of adult social care services

Whilst there is high quality research on life expectancy and mortality for people with learning disabilities in Scotland, we haven't been able to immediately source a suitable series of annual, age specific mortality estimates which would replicate the CeDR approach to this stage of the work. This might be an area of improvement which we can address through collaboration with the Scottish Learning Disabilities Observatory who have published research on the [Causes and rates of deaths in adults with learning disabilities](#). This research is likely to have utilised data which could prove useful for estimating attrition among current users of adult social care services in Scotland as it helpfully calculates and presents data on standardised mortality ratios for six age bands.

In the absence of a workable alternative at this time, we have decided to utilise the data from the original CeDR study for this stage.

Table 1: Age-Specific Mortality Estimates for adults with Learning Disabilities (CeDR 2008)

Age Group	20-29	30-39	40-49	50-59	60-69	70-79	80+
Annual mortality rate (per 1,000)	5.07	6.62	8.61	21.38	34.96	70.04	118.59

**Source:** These mortality estimates were derived from death rates recorded by the Sheffield Case Register (1998-2007), the Sutton and Merton Case Registers (2003-2007) and the Leicestershire Case Register (1993-2005). Data from Sheffield, Merton and Sutton was provided by register managers and data from Leicestershire were extracted from a [published report](#)<sup>2</sup>.

<sup>2</sup> Tyrer F, Smith LK, McGrother CW. Mortality in adults with moderate to profound intellectual disability: a population-based study. *Journal of Intellectual Disability Research* 2007;51(7):520-27.

As our replicated analysis for Scotland considers adults aged 16-19 who are current users of adult social care services, we also required an age specific mortality estimate for this group. We decided to use the same estimate as we utilised in stage 2 and therefore assumed there to be 3.88 deaths per 1,000 for young people aged 16-19.

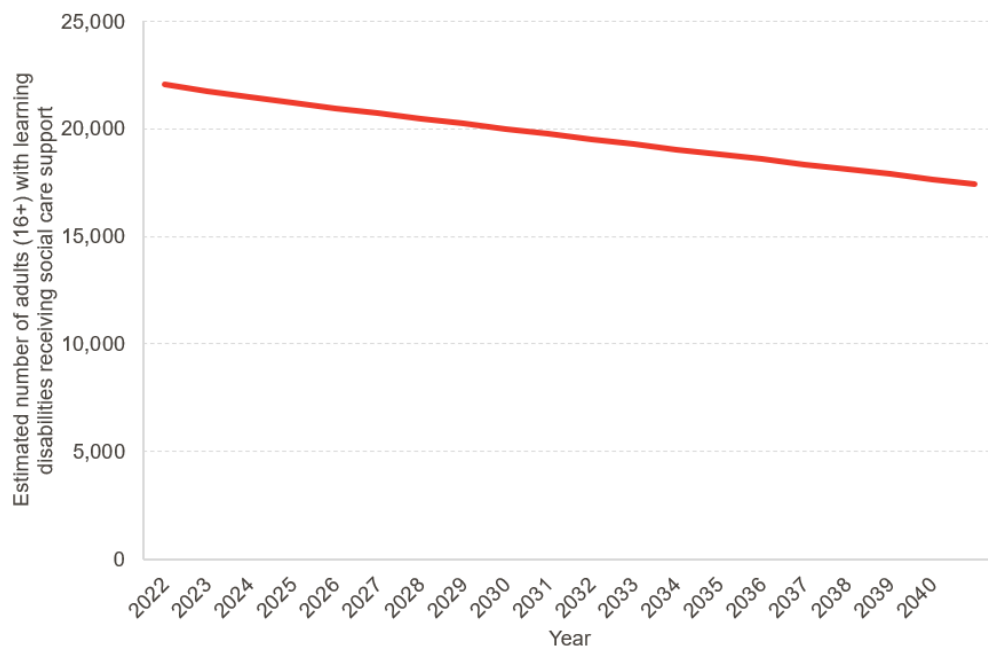
These age specific mortality rates were then applied to the corresponding age bands for the latest five years of relevant PHS: Insights in Social Care Statistics for the learning disability client group, to estimate annual adult services attrition rates. The average being 2.02% over the latest five-year period of data.

This is clearly another stage of the process where the data currently used could be improved. As previously mentioned, taking a closer look at current life expectancy and mortality research on adults with learning disabilities in Scotland is one avenue to explore. Moving forward we would also hope to be able to utilise data which would start to be generated and published through the introduction of the new annual health checks for people with learning disabilities in Scotland. This should provide additional insight on the adult learning disability population in Scotland and may also help with mortality estimates where death rate data can be drawn from registers. The Scottish Government direction to Health Boards should see these new annual health checks offered to those aged 16 and over with a learning disability by 31 March 2024.

### **Stage 6 (Results): Estimating net changes in projected adult user population**

The projection of the future number of people with learning disabilities based on the replicated analysis is presented in Figure 3. This shows a steady downward trend with the number reaching 17,444 by 2040.

**Figure 3: Projected number of adults (16+) with learning disabilities receiving social care support in Scotland (2022 to 2040)**



The calculations start with a base year of 2021 and the data from PHS Insights in Social Care Statistics for Scotland, which was discussed in stage 4. The estimate for that year was 22,049 adults (16+) with learning disabilities receiving social care support which was provided or funded by health and social care partnerships in Scotland. As we start with this data in the base year and rely on this particular data source throughout, the results shown in figure 3 could be considered as projections of the number of adults with learning disabilities receiving social care support which was provided or funded by health and social care partnerships in Scotland. This reinforces why we have framed this initial work for Scotland differently to what was produced for England.

The projected 2022 estimate is reached by firstly taking the data for 2021 and reducing it by 2.02% as per the result of stage 5 to account for annual attrition amongst current users of adult social care services over the course of the next year. The inflow was then added to this by taking the results of stage 3 which provided annual estimates of new entrants with learning disabilities to adult social care services. This provides the 2022 projection.

The same process was then repeated (2.02% reduction to the 2022 projection and the annual inflow from stage 3 added to calculate the 2023 projection and so forth...) to get the projected time series up to the year 2040.

The downward trend is essentially a result of the annual attrition estimates being consistently higher than the annual number of new entrants. This reflects an ageing population and the results of stage 1 which highlighted a potential future reduction in the number of children with a learning disability in Scotland, being driven by declining overall population estimates.

The inflow utilises data from the pupil census in Scotland and this is worth a closer look. We use 2021 data from the pupil census to fit with the availability of other sources at the different stages of this work. The latest published data as part of the 2022 school census shows that overall, there were 11,800 pupils recorded as receiving additional support needs (ASNs) due to having a learning disability. This equates to 1.7% of all pupils in 2022. Whilst overall pupil numbers have been increasing year on year over the last decade in Scotland, the number of pupils recorded as receiving additional support needs due to having a learning disability has fallen year on year. Back in 2012 this figure was almost 16,000 which equated to 2.4% of all pupils that year. This is interesting because the decrease in pupils recorded with a learning disability as the reason for ASN seems to be unique in this regard, with other categories seeing an increase over time. In particular there have been notable increases for the 'Other specific learning difficulty' and 'Other moderate learning difficulty' categories so it is possible that there has been a shift in the categorisation of pupils away from learning disability and towards one or both of these categories.

A further consideration has to be the off-flow itself i.e. the annual attrition estimates (Stage 5: Estimating attrition among current users of adult social care services). In this initial analysis, we have held the annual attrition rate flat (2.02%) over the forecast period. It could be argued that this should perhaps reduce over time (with the assumption that people, including those with learning disabilities, continue to live longer over the forecast period) which would reduce the off-flow relative to the inflow each year.

## Summary

The work described in this paper is a first attempt to estimate the future number of people with learning disabilities drawing on adult social care services in Scotland, by broadly replicating the process and analysis previously undertaken by CeDR to produce estimates of future need for England. The results of this work currently show a clear downward trajectory up to the year

2040 and whilst the stage-based approach implemented by CeDR for England has guided our analysis, the availability of relevant Scotland level data has fallen short. This is clear when comparing what CeDR were able to utilise for England in their analysis and even then, they only stated having ‘moderate’ confidence in some of the assumptions/data which they used.

For these reasons and as stated throughout, there are stages within our work for Scotland where the assumptions and the data informing these assumptions need to be revised before we can have confidence in the projection.

There are also other factors which we could take into consideration such as applying more of a social care support, regardless of the source of funding, lens to the work. Present data limitations may prove even more challenging if we look to consider eligibility measures and attempt to align more closely with the user ‘need’ framing of the work undertaken for England.

### **Next Steps & Continuous Improvement**

It has been important to highlight where data enhancements could be explored throughout this paper. This work should therefore be treated as an initial analysis which we can seek to continually improve by developing the contributory data and assumptions made across the various stages.

We look forward to future publications of the PHS Insights in social care: statistics for Scotland, Support provided or funded by HSCPs in Scotland, which we’ll use as outturn data and part of evaluating our work to date.

We have gone through an initial process of sharing this first attempt at estimating the future number of people with learning disabilities drawing on adult social care services in Scotland, with analysts from across the various data sources, the lead researchers from the original CeDR work and other relevant experts in this area such as the SLDO. This has proved extremely useful in validating our early work and gathering feedback on how data improvements can be achieved going forward.

As well as keeping the data from sources we have already utilised up to date such as Scotland’s population census, the pupil census and the PHS Insights in social care statistics, further analysis of linked data previously used by SLDO for their child and adult mortality studies has the potential to better inform this

work (stages two and five in particular). We understand that this linked dataset could provide a child mortality estimate per 100,000 for the 5–15-year-old population of interest. In relation to adult mortality data, the linked data has the potential to provide Scotland figures for Table 1 (Age-Specific Mortality Estimates for adults with Learning Disabilities) from the Scotland 2011 census and linked mortality data.

We acknowledge that the studies that were previously undertaken by SLDO were made possible by going through the appropriate processes to apply and gain approval to access the relevant linked data within Scotland's National Safe Haven. We would be keen to explore opportunities to re-visit this data for further analysis either as an extension to existing research or potentially updating previous research when microdata from the 2022 Scotland Census is made available to accredited researchers in secure settings (estimated for 2025). Both avenues being subject to appropriate approvals being granted.

Although our attempts to take a consultative approach to stage 3 (estimating the number of young people who are likely to become users of adult social care services) hasn't yielded sufficient evidence to date, we should continue to consider who we can socialise this work with. The introduction of new annual health checks to all people in Scotland aged 16 and over who have learning disabilities should also help with not only generating improved data but also identifying relevant experts to engage with.

As well as ensuring that those 16+ are offered an annual health check by 31<sup>st</sup> March 2024, Health Boards must also take all reasonable steps to identify persons within their area who are under the age of 16 and who have a learning disability, in order that an annual health check can be offered to them as soon as they attain the age of 16. Connecting this data with the social care information will mean that estimating the number of young people who are likely to become users of adult social care services should become something that the evidence base can better support going forward.

The next steps for this work are to consider the improvements we have highlighted in this section and to bring in insights from a broader range of stakeholders, including the Scottish Government. The results from this first attempt to estimate the future number of people with learning disabilities drawing on adult social care services in Scotland, should therefore be treated



with caution and discussed within the context of being an initial analysis to support data improvement efforts. The work has once again highlighted that collaboration is key and data development endeavours are unlikely to thrive unless organisations come together. It is another example of the importance of consistency (e.g., definitions) across data collections and the ability to connect data from different themes, to inform policymaking.