NIHR Policy Research Unit in Adult Social Care

Review of existing sources of evidence about people with Learning Disability

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September 2022



THE LONDON SCHOOL OF ECONOMICS AND POLITICAL SCIENCE





Acknowledgements

The research in this paper is funded by the Department of Health and Social Care through its funding for the Policy Research Unit in Adult Social Care Research. The content of this report is the responsibility of the authors and does not necessarily represent the views of the Department of Health and Social Care.

DISCLAIMER

This report is based on independent research commissioned and funded by the National Institute for Health and Care Research (NIHR) Policy Research Programme through its core support to the NIHR Policy Research Unit in Adult Social Care Research (PR-PRU-1217-21101). The views expressed are those of the authors and are not necessarily those of the NIHR or the Department of Health and Social Care.

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1. Introduction

Data from Public Health England (2016) and the Office of National Statistics (2019) suggest that there are 1.2 million people with learning disabilities (LDs) in England of whom 950,000 are adults. Seventy percent of long-term care local authority expenditure for clients between the ages of 16 and 64 supports people living with LDs (NHS Digital 2021).

The aim of this report was to identify sources of quantitative data on the population of people with LDs in England and the long-term care support they receive. It is part of a larger project which aims to improve existing evidence about the needs and support services for people with LD, describe and evaluate different approaches for maximising independence and update projection models to assess likely future trends in social care demand and expenditure for people with LDs in England.

The characteristics of people with LDs are captured by several existing data sources. These data cover need-related characteristics, formal and unpaid support received, and care outcomes achieved. Section 2 of this report lists cross-sectional or repeated cross-sectional UK or English datasets. Section 3 lists longitudinal cohorts. Section 4 lists statistical returns of administrative data. Section 5 lists population-based registers which include people living with a learning disability or registers specifically focussed on people with a learning disability. Section 6 lists datasets from other countries that could be used for comparative purposes. These include data collected in other parts of the UK but not in England. For each data source, information is provided as to the dates for which data are available (including the most recent), level of data (i.e., individual, local authority or national), the type of data and its coverage, and ownership and access to the data (where available).

2. Cross-sectional datasets

The 2017 ONS (and NatCen Social Research) *Survey of the Mental Health of Children and Personal Social Services Survey of Adult Carers in England (PSS SACE)* provides data on the impact of caring responsibilities on adult carers' quality of life. The survey takes place every other year and surveys carers aged 18 or over caring for a person aged 18 or over. The survey is limited to carers receiving support from Councils with Adult Social Services Responsibilities. This includes those receiving support directly or who are known to councils through the receipt of services by the person they care for. Of the 50,800 respondents to the 2018-19 survey, just over 20% were caring for an adult with a learning disability or difficulty. The duration and intensity of caring and experience of services are important data for valuing the time inputs of carers in the needs of persons with learning disabilities both currently and into the future. The NHS Digital Adult Social Care Analytics Hub <u>Microsoft</u> <u>Power BI</u> can be used interactively to produce summary tables. Information on access to these data, for example to do further tabulations, is not provided but enquires can be made at <u>enquires@nhsdigital.nhs.uk</u>. The *Personal Social Services Adult Social Care Survey (ASCS)* is an annual survey of the support received from adult (i.e. age 18 and over) social services, levels of satisfaction with services and quality of life of recipients of adult social care. The questionnaire contains questions to allow for analysis of whether or not the services received by social care clients are helping them to live safely and independently and the impact of services on their quality of life. The questionnaire uses some of the measures from the Adult Social Care Outcomes Framework (ASCOF) and the quality of life questions are based on the Adult Social Care Outcomes Toolkit (ASCOT). These data include an identifier of the primary support reason which includes learning disability support.

A range of demographic data are collected including age, gender, ethnicity, sexual orientation and religion. There is also data on the setting of support (i.e. community, residential care or nursing home care) and the mechanism of delivery of support (e.g. direct payment). Trends can be examined as ten years of data are available. The most recent survey, 2019-20, was the 10th in the collection and has responses from 16,340 persons with learning disability as their primary support reason. Interactive charts and visualisations of data are available on the NHS Digital Adult Social Care Analytical Hub <u>Microsoft Power BI</u>. Summary data for each question can be produced for England, or by council, broken down by age band, gender, primary support reason or ethnicity. It is not possible however to extract data for more than one of these characteristics at a time. Information on access to these data, for example to do further tabulation, is not provided but enquires can be made at <u>enquires@nhsdigital.nhs.uk</u>.

The NHS Benchmarking Network produces the *Learning Disability Improvement Standards review*, a national data collection used to assess NHS Trusts' compliance with Learning Disability Improvement Standards arising from the Transforming Care programme. Transforming Care aims to improve the lives of children, young people and adults with a learning disability and/or autism through improving their quality of care, quality of life and enhancing community capacity. The four Learning Disability Improvement Standards are respecting and protecting rights, inclusion and engagement, workforce and specialist learning disabilities services. There are three elements of the dataset: (i) Trust level data on policies, activity, the impact of the care delivered, service quality and outcomes; (ii) a staff survey on training and skills; and (iii) a patient survey on the quality of care received and the overall patient experience. The most recent report by the NHS Benchmarking Network was published in July 2019. Key national (England) statistics from the report are available online at Learning disabilities standards benchmarking report FINAL.pdf (england.nhs.uk).

Key findings from the 2020 data collection can be found at <u>Learning Disabilities — NHS</u> <u>Benchmarking Network</u>. No information is provided regarding public/research access to these data.

3. Cohort datasets

The **1970** *British Cohort Study (BCS)* follows the lives of approximately 17,000 people born in England, Scotland and Wales in a single week in 1970. It includes direct measures of child cognitive functioning at ages 5, 10 and 16. Brief cognitive tests were administered (some

drawn from validated tests of IQ), and data at age 10 were used to derive a proxy measure of IQ (Emerson et al 2018). Age 5 cognitive test results were used where data were unavailable at age 10. Using this procedure 426 individuals were identified as functioning in the IQ range associated with intellectual disability (IQ 70 or below). The BCS cohort was most recently surveyed at age 46 (in 2016). Data on the characteristics of people with LD included in the surveys cover health, health behaviours, financial status, social support and family formation. These data, collected and managed by the Centre for Longitudinal Studies at University College London, are available from the UK Data Service <u>UK Data Service</u>.

Next Steps is an annual panel study of a cohort of adolescents in England conducted by the Centre for Longitudinal Studies at University College London (UCL) and funded by the Economic and Social Research Council. It follows the lives of 16,000 people in England born in 1989-90. The study began in 2004 when the cohort members were aged 14. The cohort members were surveyed annually until 2010 and then next in 2015-16 when they were aged 25. The primary sampling unit was schools, with deprived schools over-sampled by 50 per cent.

The data from the Next Steps survey can be linked to the Department of Education (DoE) National Pupil Database to identify participants with Special Educational Needs (SEN). There are 527 children in the cohort identified as having mild/moderate intellectual disability (Hatton et al 2017). The Age 25 survey took place in 2015 and 2016. These more recent data provide information on transitions into adulthood with respect to home life and employment for young adults with learning disabilities and how these may have changed recently. Next Steps data can be accessed via the UK Data Service (<u>UK Data Service</u>). Study members were asked to take part in a survey in February 2021 about the impact of the COVID-19 crisis. This is in addition to an online COVID-19 survey conducted in 2020 across several cohort studies, including Next Steps.

The *Millennium Cohort Study (MCS; 'Child of the New Century')* follows a cohort of 19,000 young people born in England, Scotland, Wales and Northern Ireland in 2000. The study is conducted by the Centre for Longitudinal Studies. The most recent sweep was in 2018-9. It does not directly identify learning disabilities, but the presence of learning disability has been estimated using data from cognitive assessments and parent and teacher reports of special education needs and teacher-rated performance (Totsika et al 2018). Using this method, 555 children have been identified in the most recent sweep as probably having a learning disability. These data can provide nationally representative estimates of the characteristics of those entering adulthood and their likely need for services. In particular, the survey will be a good source of data on housing status, parental health, social support, comorbidities (including presence of obesity) of cohort members. These data are available by gender, ethnicity and country (within UK) and can be accessed from the UK Data Service (<u>UK Data Service</u>).

Understanding Society (UK Household Longitudinal Study) is funded by the Economic and Social Research Council and run by the Institute for Social and Economic Research at the University of Essex. UKHLS does not include information on formal diagnosis of intellectual disability or borderline intellectual functioning (Hatton et al 2017). Estimating the presence of intellectual impairments (as a proxy for intellectual disability and borderline intellectual

functioning) has used the results of cognitive tests conducted as part of the wave 3 interview and self-reported educational attainment data. This method identified 263 adults as having intellectual impairments and an additional 1,785 adults as having borderline intellectual impairments. In addition to demographic data, UKHLS also has data on each cohort member's level of disability (activities of daily living and instrumental activities of daily living, receipt of unpaid and formal care (including source of care), health state and biomarkers that may be used to predict future illness. Social care receipt data is available at Wave 7 (2015-2017) and Wave 9 (2017-2019) and will be available in Wave 11 when these data are released in 2021. These data are available from the UK Data Service (<u>UK Data Service</u>).

4. Administrative data

The *Adult Social Care Finance Return (ASC-FR)* and *Short and Long Term Support (SALT)* are annual, aggregated data for councils in England on expenditure on social care services for adults aged 18 and over and the receipt of social care services, respectively. These data are broken down by primary support reason, one of which is learning disability. For the last three years, findings from these two data sources have been published alongside each other in the Adult Social Care Activity and Finance Report. The most recent report is available online at:

https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-careactivity-and-finance-report/2019-20.

The SALT Collection reports the number of clients receiving learning disability support in two age groups, 18 to 64 and 65 and over. The finance data provides total annual expenditure and weekly costs of social care for people with LD for two categories of services (residential care and community care) and for the two age groups mentioned above. These data also include the number of assessments of people with LD, the number of carer assessments among households where an adult with LD was living in the community, the number of carers receiving support, the number of working age adults with LD in paid employment and the living situations of working age adults with LD https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/social-care-collection-materials-2022#short-and-long-term-support-salt-. These data can be broken down into short-term and long-term care and is available annually, allowing for trends to be examined.

Clinical Practice Research Datalink (*CPRD*) is a UK wide GP practice dataset which contains primary health care data from patient electronic records. It can be linked to Hospital Episode Statistics. It covers 16 million patients currently registered with the participating GP practices (45 million former patients are also included). Since these data are captured over time, they can be used for longitudinal analysis of trends in the number of people with LD and their consultations with GPs and practice nurses, referrals to outpatients and prescriptions. The dataset contains 20 years of follow-up data for 25% of the patients in the CPRD. The anonymised patient data, which are held by the Medicines and Healthcare Products Regulatory Agency, may be requested via the Independent Scientific Advisory Committee. **DWP Benefit Statistics** can be analyses through their Stat-Explore tool <u>https://stat-</u><u>xplore.dwp.gov.uk/webapi/jsf/login.xhtml</u>. The number of recipients of various disability benefits can be broken down by age, gender and by region, local authority, super output area, census output area, Westminster Parliamentary Constituency or ward. The data are available per quarter.

NHS Digital produces the **Health and Care of People with Learning Disabilities Experimental Statistics**. These are annual statistics, first produced in 2015/16, based on GP records from over half of GP practices in England. The aim of the collection is to provide information about the key differences in healthcare between people with a learning disability and those without. The statistics cover a range of health-related variables aggregated at regional, CCG or LA/council levels and some of the data are presented by age band and sex. Data from people recorded by their GP as having a learning disability and a control group of people recorded as not having a learning disability are included. The most recent 2019/20 collection introduced new indicators, making comparison with previous versions difficult https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2019-to-2020.

OpenSAFELY is a secure analytics platform for electronic GP health records in the NHS. It was created to provide data for responding to the Covid-19 pandemic. Initial reports have included summary data on vaccination coverage among people with LD aged 16 to 64, with the tables broken down by sex, age band or ethnicity. Access approval is required to analyse the OpenSAFELY data. Access requirements can be found at:

<u>https://www.opensafely.org/onboarding-new-users/</u>. The OpenSAFELY data has also been used in a paper on the risks of COVID-19 hospital admission and death for people with learning disabilities (Williamson et al., 2021).

5. Registers

The **Assuring Transformation (AT)** dataset is a commissioner-based return for inpatients in a hospital setting with learning disabilities and/or autism. Reported monthly, the data are collected and published by NHS Digital. Data are reported by English commissioners and are focused on people in 'specialist' inpatient units commissioned by English NHS commissioners (but could be in inpatient services outside England). The data can be broken down by sex, age band, ethnicity and usual place of residence (e.g. private dwelling, Monthly statistics and a meta data file are available on the NHS Digital Assuring Transformation website: https://digital.nhs.uk/data-and-information/data-collections-anddata-sets/data-collections/assuring-transformation/reports-from-assuring-transformationcollection.

As of the end of March 2015 there were 262,446 people of all ages on *General Practice Learning Disability (GP LD)* registers. The register is sometimes referred to as the Quality Outcomes Framework (QOF) Register. Prevalence estimates suggests that only 23% of adults with LD in England are identified as such on GP registers. Thus, these registers may not identify all people with LD using services due to poorer health, lack of social participation, unemployment or psychological distress. This may not be a significant issue for studying adult social care need, however, as social care is focussed on those with more severe LD which should be better identified in GP LD registers. A small number of summary statistics from the register are published on the NHS England and NHS Improvement website. These include that only 55% of patients with a learning disability received an annual learning disability health check. QOF data are available for each GP practice in England.. Detailed tables of GP-registered numbers and prevalence at national, regional, Sustainability and Transformation Partnership, Clinical Commissioning Group and GP practice level are available. The link for 2019-20 data is: <u>https://digital.nhs.uk/data-andinformation/publications/statistical/quality-and-outcomes-framework-achievementprevalence-and-exceptions-data/2019-20</u>

The Mental Health Services Data Set (MHSDS) includes data on each person that receives a specialist secondary mental health service or specialist learning disabilities or autism spectrum disorder service if the service was fully or partly funded by the NHS. Reporting is optional for services that are not funded by the NHS. Monthly statistics are produced from the MHSDS (since January 2016) and published on the NHS Digital website. The December 2021 release estimates the number of individuals in contact with learning disabilities and autism services as 175,000. Monthly data broken down and reported by provider organisation is available from the NHS Digital website (Statistics about mental health, learning disabilities and autism services - NHS Digital). It does not include Improving Access to Psychological Therapies (IAPT) services. Access to these data is via the NHS Digital Data Access Request Service (DARS; Data Access Request Service (DARS) - NHS Digital).

Department of Education Special Educational Needs (SEN) data from the **National Pupil Database (NPD)** identifies children who have a statement of Education Health and Care Plan and separately identifies children who receive SEN Support. SEN data can be broken down by age, gender, ethnicity and severity of LD which will be useful for modelling future needs. Trend data is also available, as is national data broken down by local authority. Summary data is available on the Gov.UK NPD website (Find and explore data in the National Pupil Database - GOV.UK (education.gov.uk)).

The NPD includes data from the Department for Education School Census. *The School Census* was previously used by Emerson et al (2012) to estimate the number of children in England with SEN associated with learning disability and likely to go on to become eligible for adult social care services. It is a statutory return that schools are required to complete three times per year. The *Department of Education Health and Care (EHC) plan (EHCP)* has replaced the SEN system. Previous analysis found that the change in system from SEN statements to EHC plans has not had a significant impact on the number of children requiring specific support (Hatton 2020)

The *Safeguarding Adults Return* is published by NHS Digital. It provides estimates of the number of individuals in England receiving learning disability support who are involved in Section 42 safeguarding enquiries (where a concern is raised about a risk of abuse leading to an investigation under safeguarding procedures in accordance with Section 42 of The Care Act 2014). Summary data are available by council are reported in Safeguarding Adults, England, 2020-21 and available on the NHS Digital website at: https://digital.nhs.uk/data-and-information/publications/statistical/safeguarding-adults/2020-21# and are available for

several previous years. These are labelled as Experimental Statistics due to local variation in how safeguarding activity is defined and reported.

The Sheffield Case Register is a list of people in Sheffield with learning disabilities with an estimated coverage of at least 90% of the population with learning disabilities. It was used by Emerson et al (2014) to estimate trends in the age-standardised mortality rate and life expectancy of people with learning disabilities in Sheffield using data for a period of 33 years. These trends were compared to trends for the general population in England and Wales using ONS data. These data also include information on ethnicity, secondary diagnoses or medical conditions, carers, living situation and employment status. These data have been used in projections. Burns (2013) estimated that the number of adults with moderate or severe learning disabilities will rise by over 27% between 2012 and 2022; that the number of young adults (age 20 to 30) with LD will rise by 90%; and that the number of over 65s with a LD will rise by 48% between 2012 and 2022. These data are available for research [Learning Disability Service - Case Register] Sheffield Directory].

Deprivation of Liberty Safeguards (DoLS) data is available from NHS Digital. These safeguards ensure individuals who lack capacity to consent to arrangements for their care have the arrangement independently assessed to ensure they are in the best interest of the individual concerned. Summary data for each year by council and service type (e.g. mental health, care home etc) are available in the report Mental Capacity Act 2005, Deprivation of Liberty Safeguards - 2020-2, and available onlin on the NHS Digital website at https://digital.nhs.uk/data-and-information/publications/statistical/mental-capacity-act-2005-deprivation-of-liberty-safeguards-assessments/2020-21

The Learning Disability Inpatient Census was last conducted in 2015

(https://digital.nhs.uk/data-and-information/publications/statistical/learning-disabilitiescensus-report/learning-disability-census-report-england-30th-of-september-2015). Its aim was to collect information from specialist inpatient service providers in England on people with learning disabilities and/or autism in their service (on a specific day – 30th September). It includes people with LD in English inpatient services whose placements were commissioned from outside England but does not include people with LD in inpatient services commissioned by English commissioners but placed outside England. The census was also conducted in 2013 and 2014. Similar censuses were conducted in Scotland (most recently in 2019), Wales (2019; https://statswales.gov.wales/Catalogue/Health-and-Social-Care/Mental-Health/Psychiatric-

Census/patientsinmentalhealthhospitalsinwaleswithalearningdisability) and Northern Ireland (2018-19; https://www.health-ni.gov.uk/news/mental-health-and-learning-disability-inpatients-2018-19).

Learning Disability Mortality Review (LeDeR) annually reports summary data on deaths of persons with learning disabilities in England reported by Clinical Commissioning Groups across England. Based on estimates from Public Health England of the number of deaths of people with learning disabilities of all ages each year, the LeDeR 2018 Report estimated that they were notified of approximately 86% of deaths. As the aim of LeDeR is to improve services for people with learning disability and autistic people, they undertake a review of the life of each person with a learning disability and/or who are autistic who died. The

review looks at the health and social care services they received throughout their life through speaking with a family member of the person who died. The 2020 LeDeR Report states that: "By 31st December 2020, 92% of deaths notified to the programme between 1st January 2018 and 30th June 2020 had been reviewed".

These data, held by NHS England, includes both regional and national information. Annual reports from 2015 to 2020 are available on the School for Policy Studies, University of Bristol website (http://www.bristol.ac.uk/sps/leder/uob-2015-21/). Based on data from current and previous reports, trends in mortality (i.e. age at death) and place of death can be examined. These data are also available by age group, sex, ethnicity, level of severity of LD and comorbidities. Public Health England used data from the LeDeR and NHS England's COVID-19 Patient Notification System to estimate the number of people in England identified as having learning disabilities who died from COVID-19 from the start of the pandemic to 5th June 2020.

6. Datasets from other countries

Scotland, Wales and Northern Ireland

Inpatient censuses conducted in Scotland, Wales and Northern Ireland are mentioned above.

The *Scottish Census*, conducted (as in England) every 10 years, asks individual respondents if they have any of a number of conditions related to health and disability, expected to last at least 12 months, from a list that includes identifies learning disability. This distinguishes it from the England census in which the individual questions ask about the presence of a physical or mental health condition or illness but does not ask about the nature of the condition. The Scottish data can be broken down to determine the prevalence of learning disabilities by age and gender. The Scottish Learning Disabilities Observatory has done analysis of these data <u>https://www.sldo.ac.uk/census-2011-information/learning-disabilities/</u> These data can be used to compare rates of the prevalence of LD within the population in England – currently best estimated from local registers such as the Sheffield Case Register. The Scottish Census data is available from its Data Warehouse (statisticscustomerservices@nrscotland.gov.uk).

Learning Disabilities Statistics Scotland has national and local authority statistics about adults with learning disability who are known to local authorities in Scotland. This dataset is managed by the Scottish Commission for People with Learning Disabilities and Public Health Scotland. An annual report is produced from these data, the latest being the 2019 report (2019 Report - SCLD). Trends can be estimated using previous annual reports which date back to 2008. The national data can be broken down by gender, ethnicity, accommodation type, whether co-resident with a carer and other factors. No information is provided as to accessing the individual level data. SCLD and <u>Public Health Scotland</u> (formerly Information Services Division (ISD)) have worked together over the past three years to merge LDSS into the Source Social Care data collection. **StatsWales** produces statistics, by local authority, of the number of persons with LD by service and age range. The most recent collection is for 2020-21 and available at: https://statswales.gov.wales/Catalogue/Health-and-Social-Care/Social-Services/Disability-Registers/personswithlearningdisabilities-by-localauthority-service-agerange. Annual data is available from 2001-2.

Canada

The **Transitions Longitudinal Study**, in Ontario, Canada, began as a follow-up to the evaluation of pilot projects which sought to create a level playing field for post-secondary students with learning disabilities in Ontario which were part of the Learning Opportunities Task Force programme. In order to assess to what extent the success with post-secondary education pilots would translate into success in employment, career and social aspects. A total of 1242 students with learning disabilities were included in the pilots, from which 210 agreed to participate as the initial cohort for the longitudinal study in 2004. The study ended in 2011. These data provide a basis for what improvements in education, employment and social participation are achievable with targeted interventions (includes, for example, an assigned disability coordinator). For further details see McCloskey et al (2011) https://carleton.ca/fita/wp-content/uploads/Year-7-Annual-Report.pdf.

As part of the *Health Care Access and Developmental Disabilities Program*, Lunsky et al (2019) studied the health care costs of a population-based cohort using data provided by, and analysed at, ICES in Toronto, Ontario, Canada. ICES is an independent organisation that reports on the health and health care utilisation of Ontario residents. The cohort was assembled by searching for all intellectual and developmental disabilities (IDD) diagnostic codes available through health data. The cohort included only those individuals aged 18 to 64 to allow for individuals to also be identifiable through the disability income support data as part of data linkage. Lunsky et al (2019) estimate health care costs for the cohort and identify factors associated with having high or low costs, where high and low are defined by cost thresholds for the overall adult population under age 65.

Intellectual Disability Exploring Answers (IDEA) database covers Western Australia and provides estimates of the prevalence of learning disability and autism in Western Australia. The database is of a cohort of children born between 1983 and 2010 who were diagnosed as having intellectual disability and/or autism spectrum disorders by the Disability Services Commission or educational sources. Petterson et al (2005) describe the database in detail. A paper by Bourke et al (2016) found that the prevalence of intellectual disability in Western Australia within the cohort was 17.0 per 1000 (Note that some of the cohort are as young as age 5, so diagnosis may not have yet occurred). The prevalence of severe intellectual disability was estimated as 1.2 per 1000. The authors reference a meta-analysis by Maulik et al (2011) that estimated the prevalence of intellectual disability as 18.3 per 1000 based on population-based studies. See also: <u>https://questioning-</u>

answers.blogspot.com/2016/06/prevalence-of-learning-disability-and-autism-westernaustralia.html.

7. Conclusions

The range and breadth of data on the lives of people with learning disability has expanded in recent years but gaps remain in what is known about their quality of life and well-being and the level of support they receive from social care services and unpaid carers.

Much of the available data, such as the National Pupil Database, the Department of Education Health and Care Plan and the Survey of the Mental Health of Children and Young People, focuses on identifying the prevalence of learning disability and autism among children of school age and their educational needs.

Less is known about the prevalence of learning disabilities in the adult population. National registers such as the General Practice Learning Disability register will hopefully over time expand their coverage. For now, local registers such as the Sheffield Case Register, may be the best source for estimating LD prevalence amongst adults in England. Additionally, data is needed to permit estimation of the numbers of people with LD in a wide range of care settings.

Several data sources exist on the use of LD services. The Learning Disability Improving Standards review, Mental Health Services Dataset, Adult Social Care Finance Return and Short and Long Term Support return all provide a wealth of data on service use aggregated to local authority or provider organisation level. Also, much can be learned from the Learning Disability Mortality Reviews.

Quite rightly, these data are strictly protected. Greater clarity on access may make research using these data more feasible. National cohort datasets are generally easier to access but the subsamples of people with LD and/or autism are relatively small. The cohort datasets do, however, provide a wider range of demographic data.

Further research is critical to aid policy makers and service providers identify and meet the needs of people with learning disability. The current Coronavirus pandemic has tragically illustrated the harm that can result from not being able to respond adequately to the needs of those with learning disability as can be done for the general population.

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