



Public Health
England

Protecting and improving the nation's health

Learning Disabilities Observatory

People with learning disabilities in England 2015: Main report

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About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. We do this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. We are an executive agency of the Department of Health, and are a distinct delivery organisation with operational autonomy to advise and support government, local authorities and the NHS in a professionally independent manner.

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Summary

About the Learning Disabilities Observatory

The Learning Disabilities Observatory (also known as Improving Health and Lives (IHaL)) was set up in April 2010 to provide high quality data and information about the health and healthcare of people with learning disabilities. The information helps commissioners and providers of health and social care to understand the needs of people with learning disabilities, their families and carers, and, ultimately, to deliver better healthcare.

The Public Health England Learning Disabilities Observatory is a collaboration between Public Health England (PHE), the Centre for Disability Research at Lancaster University and the National Development Team for Inclusion.

National statistical information on the characteristics of people with learning disabilities, and the services and supports they and their families use, is collected by several government departments. The aim of this report is, within a single publication, to provide a concise summary of this information.

This report, the fifth in a series, reports the most recent data available at the time of writing (typically for 2014/15) for people with learning disabilities in England. The main report has an accompanying report of detailed data tables, and is in 12 chapters. Each of these chapters is summarised below.

The number of people with learning disabilities in England

By combining information collected by government departments on the presence of learning disabilities among people using services, overall population predictions for England and the results of epidemiological research, we estimate that in England in 2015 there were 1,087,100 people with learning disabilities, including 930,400 adults.

The number of people with learning disabilities recorded in health and welfare systems is much lower, for example GPs identified 252,446 children and adults as having learning disabilities on their practice-based registers.

Mortality

Information from a range of sources consistently reports that people with learning disabilities in England die much younger than the general population (13 to 20 years younger for men with learning disabilities; 20 to 26 years younger for women with

learning disabilities). As with the general population, the median age of death for people with learning disabilities is increasing.

More than three times the number of people with learning disabilities die than would be expected when taking into account age and sex. The three most common causes of death for people with learning disabilities are circulatory diseases (22.9% of deaths), respiratory diseases (17.1%) and neoplasms (cancers) (13.1%).

Health services

Information is available on the extent to which people with learning disabilities are accessing a range of mainstream and specialist health services.

The number of people with learning disabilities in England eligible for and receiving a learning disability annual health check continues to rise (partly due to the minimum age extending to 14 years of age) with 124,785 health checks done in 2014/15 (52.2% coverage) and substantial geographical variation.

Compared to people without learning disabilities, people with learning disabilities are more likely to use a wide range of general hospital services, particularly paediatrics, dentistry and psychiatry, with substantial geographical variation.

In 2014/15 there were a total of 98,005 outpatient consultations under the speciality of learning disability psychiatry, largely face-to-face ongoing appointments. There were also 12,335 in-patient consultations under the speciality of learning disability psychiatry.

The Learning Disability Census reported 3,000 people in specialist learning disability in-patient services at the end of September 2015, a reduction of 7.7% from 2013, with substantial geographical variation.

Education

In 2014/15, 70,065 children in England with a primary need associated with learning disabilities had a statement of special educational needs/education health and care plan. Of these, 44% were identified as having moderate learning difficulties (MLD), 41% severe learning difficulties (SLD) and 15% profound and multiple learning difficulties (PMLD).

While the number of children identified as having a primary need of SLD and PMLD has been increasing in line with increasing school rolls since 2009/10, the number of children identified as having a primary need of MLD has dropped by 24% in total from 2009/10 to 2014/15. An increasing proportion of children with MLD, SLD and PMLD are being educated in special schools.

Children's social care

In 2014, just over one in four of 'looked after' children had a special educational need associated with learning disabilities. The risk per 1,000 children of being looked after at 31 March 2014 was five per 1,000 for all children, 23 per 1,000 for children with MLD, 31 per 1,000 for children with SLD, and 40 per 1,000 for children with PMLD.

Adult social care

There were substantial alterations to the structure of the data collected about social care statistics that came into operation in April 2014. There were changes to the categories of activity counted, the approach to designating individuals' main reasons for receiving support, and a different approach to estimating the total number of people in the group for whom services could be relevant. To minimise the comparability difficulties we have thus presented numbers of people receiving types of support as opposed to the more usual rates per thousand population.

In 2014/15, the most common living situation for adults with learning disabilities getting long-term social care support was settled living with family/friends (44,785 people). 23,215 people were living in registered care homes, 23,075 people in supported accommodation, 12,425 people in tenancies with local authorities, housing associations or registered social landlords and 1,195 people in sheltered/extra care housing.

In 2014/15, 83,995 adults with learning disabilities aged 18 to 64 years were reported by local authorities to be using some form of self-directed support, most commonly a council managed personal budget (49,150 people).

In 2013/14 (the last year such data were collected), overall 117,025 adults with learning disabilities were using some form of community service, most commonly day services (49,555 people), home care (43,025 people), professional support (21,035 people), and equipment and adaptations (11,095 people).

In terms of social services gross current expenditure in 2014/15, for adults aged 18 to 64 years the biggest category of long-term support expenditure was residential care (£1.7 billion), followed by supported living (£933 million), other long-term community support (£613.2 million), direct payments (£454 million), home care (£349 million), supported accommodation (£274 million) and nursing care (£58 million). Compared to the £4.4 billion in total spent on long-term support for working age adults with learning disabilities, £60 million in total was spent on short-term support.

For adults with learning disabilities aged 65 years or more, £534 million in total was spent on long-term support and £6 million on short term support.

There was substantial geographical variation in the provision of every form of social care service and in average expenditure on social care support.

Employment

The number of adults with learning disabilities in any paid/self employment was 7,430 people in 2014/15, with most people (71%) working less than 16 hours per week.

Safeguarding

In 2014/15 safeguarding referrals were made for 15,715 people with learning disabilities, with a consistent decrease from 2011/12 to 2014/15.

Deprivation of Liberty Safeguards (DoLS)

From 2009/10 to 2013/14 the number of completed DoLS applications regarding adults with learning disabilities stayed reasonably stable (1,550 applications in 2009/10; 1,403 applications in 2013/14). Following the 'Cheshire West' Supreme Court judgement in March 2014, the number of DoLS applications regarding people with learning disabilities increased dramatically to 16,645 in 2014/15.

Benefits

In terms of benefits for working age adults, in May 2015 387,050 adults with 'learning difficulties' (a broader group than people with learning disabilities) were receiving Disability Living Allowance (DLA), with numbers consistently increasing year on year. For most people, DLA is gradually being replaced by Personal Independence Payments (PIP), where the number of people with 'global learning disabilities' is small but rapidly increasing (from 8,233 people in March 2015 to 24,340 people in March 2016).

Attendance allowance is paid to disabled people over the age of 65 to help with personal care. From 2002 to 2015, the number of people with 'learning difficulties' claiming Attendance allowance has declined by 2.8% per year to 1,250 people in 2015.

Family carers

From 2007/08 to 2014/15, there has been a reduction in the number of family carers of an adult with learning disabilities getting a service for themselves as carers, with the number of family carers getting information/advice/signposting plateauing from 2010/11.

Of the 14,015 family carers in 2014/15 getting a service: 7,675 carers had a direct payment only, 2,010 carers had a service with part direct payment, 2,065 carers had a

council managed personal budget and 2,265 carers had other council support. An additional 14,375 family carers had support in the form of information/advice/signposting/universal service only and 10,265 family carers had no direct support at all.

Over half (51.4%) of 6,160 surveyed family carers of an adult with learning disabilities (almost all of whom lived with the family carer) spend 100+ hours a week caring for that person, almost three quarters (74.3%) had been in a caring role for over 20 years and almost a third (30.2%) are not in paid employment due to their caring responsibilities.

Introduction

National statistical information on the characteristics of people with learning disabilities, and the services and supports they and their families use, is collected by several government departments. The aim of this report is, within a single publication, to provide a concise summary of this information and to provide links to key data collections.

All the information contained in this report relates to people with learning disabilities in England. Most of the data sources are based on returns related to the entire relevant population of people in England, rather than samples of people with learning disabilities (representative or otherwise). We have clearly indicated where the information is based on a sample rather than a national population.

In each area we have reported the most recent data that is available. In most instances this relates to activity in 2014/15. Wherever possible we have also included data from previous years in order to identify trends over time. In many instances, however, this has been problematic due to changes in the way that data has been collected over time.

This report is the fifth in an a series. Previous reports are:

- People with learning disabilities in England 2010¹
- People with learning disabilities in England 2011²
- People with learning disabilities in England 2012³
- People with learning disabilities in England 2013⁴

In previous years' reports, the detailed data tables have been included within the main body of the report. This year, to improve readability, more information is summarised in graphical form and the data tables are in a separate report. All tables referred to throughout this report are contained in the separate data tables report.

Detailed local information and comparisons for many of the indicators in this report are available in Public Health England's Learning Disability Profiles, available here fingertips.phe.org.uk/profile/learning-disabilities

Enquiries about the information contained in this report should be directed to ldt@phe.gov.uk

The number of people with learning disabilities in England

There is no definitive record of the number of people with learning disabilities in England. No government department collects comprehensive information on the presence of learning disabilities in the population and learning disabilities are not recorded in the decennial Census of the UK population.

It is, however, possible to estimate the number of people with learning disabilities in England by combining information collected by government departments on the presence of learning disabilities among people using particular services, overall population predictions for England and the results of epidemiological research.

Children with learning disabilities

The Department for Education (DfE) collects information on the special educational needs (SEN) of all children in maintained schools and non-maintained special schools (see Chapter 5 for more detail). Children not included in this dataset include children being educated at home, children educated in independent (non-state funded) mainstream schools and children educated in profit making independent special schools. Three types of SEN, when combined, are approximately equivalent to learning disabilities: moderate learning difficulty (MLD), severe learning difficulty (SLD) and profound multiple learning difficulty (PMLD).

In 2014/15, 70,065 children in England had a statement of SEN or an education health and care plan (EHC plan) and were identified as having a primary SEN associated with learning disabilities. The collection of information on children with SEN who do not have a statement/EHC plan is currently in a state of transition. However, in 2013/14 100,910 children in England were identified in the School Action Plus category and were identified as having a primary SEN associated with learning disabilities but not a statement or EHC plan.

Combining these two estimates (170,975 children) gives an estimated prevalence of learning disabilities of 2.5%. This estimate is somewhat higher than the results of meta analyses of existing epidemiological research¹, but is not inconsistent with the theoretical prevalence of learning disabilities based on the expected distribution of intelligence within the population and some recent epidemiological research undertaken in England².

Adults with learning disabilities

Three approaches can be taken to estimate the numbers of adults with learning disabilities in England. These are based on:

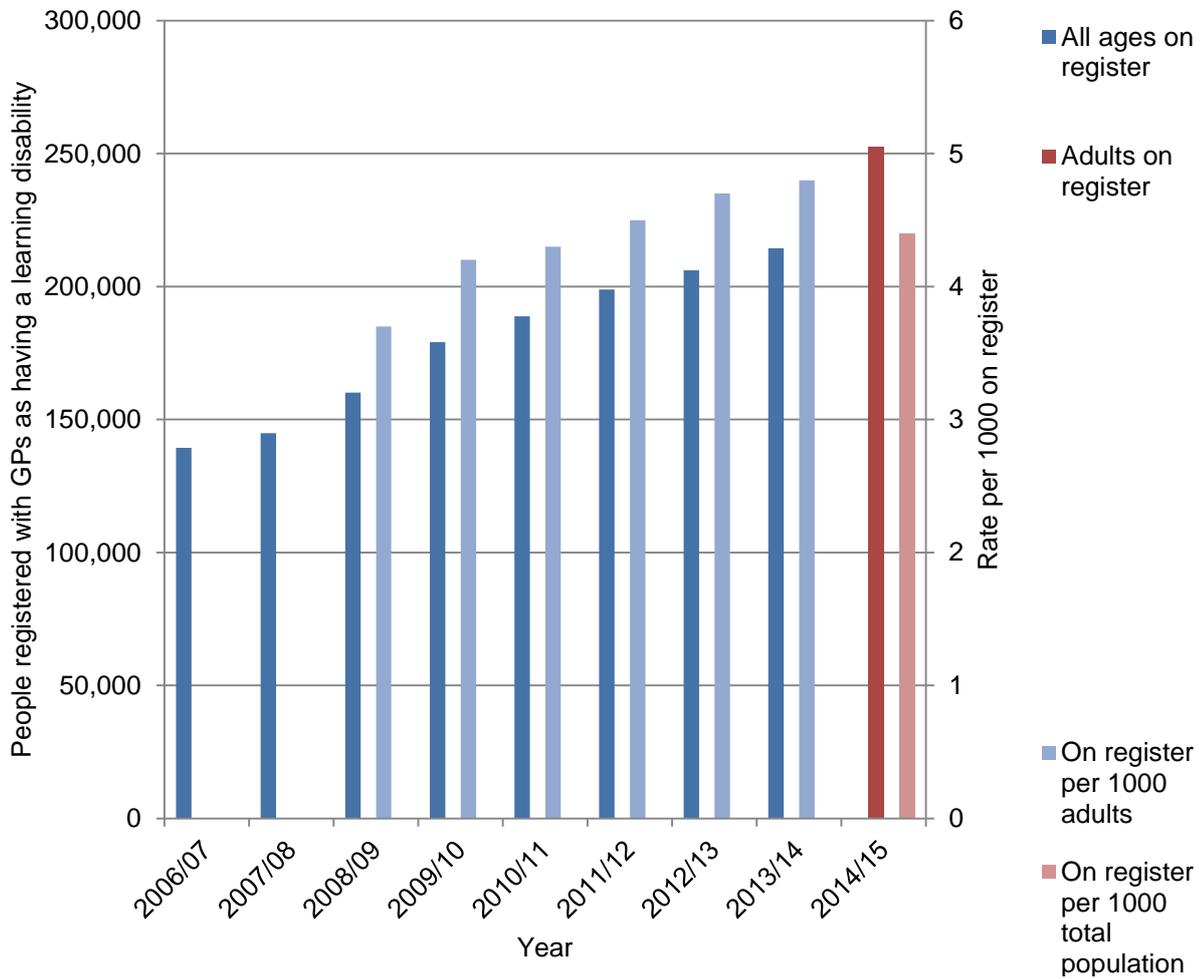
- the number of people using learning disabilities services
- the number of people known to learning disabilities services or known to GPs
- the estimated number of people with learning disabilities in the population.

It is possible to identify the number of adults who use some specific services for people with learning disabilities. For example, councils with social services responsibilities report the number of adults who have received long-term social care support in any given year (see Chapter 7 for further details).

A larger number of people with learning disabilities are identified as such on GP registers. GPs are asked to keep a register of people registered with them who they know to have learning disabilities. These learning disability registers were established in 2006 to 2007 as part of the quality incentive scheme called the Quality and Outcomes Framework (QOF). Up until 2013 to 2014, QOF learning disability registers included only people aged 18 or over. In 2014 to 2015, their scope was officially expanded to cover people with learning disability of all ages. However, it is apparent that the completeness of GPs recording of learning disabilities in children and young people is less complete than for adults.

The most recent published count gives the numbers at the end of March 2015. At this point there were 252,446 people of all ages on learning disability registers. This is equivalent to 4.4 people per 1,000 population registered with a GP. Figure 2.1 shows how these numbers have changed over the period since registers were set up (see data table report Table 2.1 for details). In the early years, registers expanded sharply, probably reflecting the progressive inclusion of people known to GPs but whose case notes had not previously indicated their learning disability according to the codes required for the register. Since this early spurt numbers have continued to grow by around 4% per year.

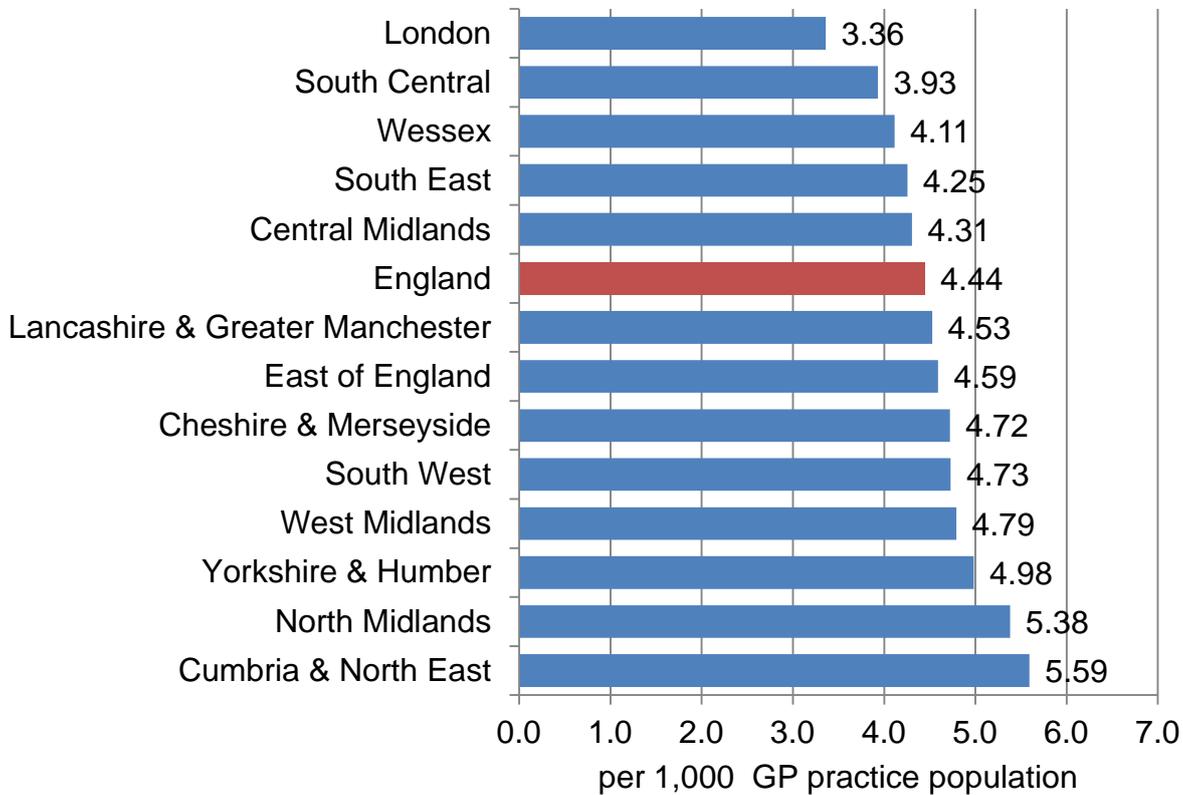
Figure 2.1. Numbers of people on GP learning disability registers, and prevalence per 1,000 people, England, 2006/07 to 2014/15



The reasons for the continuing rise are not clear. There are two obvious possible explanations. First, it may simply reflect greater recognition by GPs of people on their lists who have learning disability. A likely driver for this would be increasingly effective transition arrangements at the point of school leaving. If this is correct it should be identifiable partly in a shifting age and disability profile attributable to new registrants. Second, the rise may reflect a real increase in the current population with learning disabilities. Possible explanations for this could include an increase in additions – possibly from greater numbers surviving very premature birth – or a decrease in mortality. We will show in Chapter 3 that the age at death for this group is rising. This is likely to explain some of the rise in prevalence numbers.

Figure 2.2 shows how the prevalence of people known to GPs as having learning disabilities varies across the country. Prevalence is highest in Cumbria and the North East and the North Midlands and lowest in London. Low prevalence figures for London may be partly attributable to London local authorities placing Londoners with learning disabilities in more affordable housing and residential care services outside the capital.

Figure 2.2. The number of people with learning disabilities on GP registers as a proportion of the total GP practice lists, NHS England sub-regions, 2014/15.



Data for 2013/14 indicates that 214,352 adults in England aged 18+ were deemed eligible for annual health checks. This is equivalent to 0.5% of the estimated adult population of England in 2014. This is, however, a poor estimate of the actual number of adults with learning disabilities in England.

First, people may use services intermittently. Second, it is clear that the majority of adults with learning disabilities simply do not use learning disability services. For example, the administrative prevalence of learning disability (ie the number of people known to services as people with learning disabilities) drops precipitously from approximately 2.5% among children in the education system (see Chapter 5) to approximately 0.6% among adults aged 20 to 29.³ It is highly implausible that such reductions in prevalence can be accounted for by either reduced life expectancy (see Chapter 3) or sudden improvements in intellectual functioning. Rather, it is likely that they reflect the impact of a combination of factors which include:

- an increased threshold used for health/disability identification and surveillance by post-education health and social care agencies

- the operation of eligibility criteria to ration access to specialised social care supports for adults with learning disabilities
- the stigma associated with learning disability leading to an unwillingness for people with learning disabilities to use specialised services or self-identify as having learning disabilities
- the less obvious disabling impact of the intellectual impairments associated with learning disabilities in non-educational settings

Previous research commissioned by the Department of Health estimated that in 2004, 828,000 adults in England were likely to have learning disabilities^{4, 5}. Applying these prevalence estimates to population predictions for 2015 suggests that 1,087,100 people in England have learning disabilities, of which 930,400 are adults (aged 18+). The latter is equivalent to 2.16% of the English adult population.

These estimates suggest that only 23% of adults with learning disabilities in England are identified as such on GP registers, the most comprehensive identification source within health or social services in England. The remaining 77% have been referred to as the 'hidden majority' of adults with learning disabilities who typically remain invisible in data collections used in this publication⁶⁻⁹.

It is important to keep in mind, however, that people with learning disabilities who are not known to or who do not use specialist services for people with learning disabilities may still have some significant health care and support needs. For example, a follow-up of the National Child Development Study cohort to age 33 indicated that people with mild learning disabilities were significantly more likely than their peers to be still living with their parents, be unemployed, have literacy and numeracy problems and to experience high levels of psychological distress¹⁰. Similarly, analysis of the health of adults with learning disabilities who participated in the 2003/4 national survey Adults with Learning Disabilities in England, but who did not use specialist services for people with learning disabilities, indicated that they were more likely to smoke tobacco and less likely to access some health services and health promotion activities than those who do use these services and that they were more likely to be exposed to some known social determinants of poorer health (greater material hardship, greater neighbourhood deprivation, reduced community and social participation)⁸.

More recently, analysis of the health and wellbeing of adults with (predominantly mild) learning disabilities who have participated in major UK surveys (and are probably unlikely to be users of specialised learning disabilities services) has reported higher rates of physical and mental health problems and more problematic health behaviours when compared to participants without learning disabilities¹¹⁻¹⁵.

Mortality

This chapter summarises information about mortality. It outlines the work and findings of the Confidential Inquiry into Premature Deaths of People with Learning Disabilities. It describes briefly the findings of the independent Mazars report on deaths of people in the care of Southern Health NHS Foundation Trust following the death of a young man with learning disabilities and autism, Connor Sparrowhawk.

The chapter goes on to describe two approaches to identifying the extent of excess mortality in people with learning disabilities in England. One is based on death certificates and updates and expands an analysis provided in earlier editions of People with Learning Disabilities in England. The other is a new study we have undertaken this year. This uses GP learning disability registers, linking these to national mortality data in a sample set of practices providing anonymised data for research.

Finally the chapter outlines plans to extend this work to provide more detailed national coverage.

The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)

The most detailed review to date of the circumstances of deaths of people with learning disabilities in an English setting was the Confidential Inquiry.¹ The inquiry studied all deaths in a two year period of people known to have had a learning disability, who were resident in five primary care trust areas in the South West of England with a combined total population of 1.7 million. Routinely recorded data such as certified causes of death were obtained but, in addition, the inquiry undertook a detailed review of each death, contacting relevant informants from health and social care services, family carers and other relevant sources. A comparison sample of people without learning disabilities was studied using the same methods. All available evidence was discussed by a multidisciplinary overview panel which attempted to establish whether deaths were 'premature'. They defined premature death as when 'without a specific event that formed part of the 'pathway' that led to death, it was probable that the person would have continued to live for at least one more year'.

The inquiry studied the deaths of 249 people with learning disabilities and 58 comparators. The median age at death for people with learning disabilities (the age by which half of those studied had died) was 65 for men and 63 for women. This was 13 years younger than the national figure for men in the general population, and 20 years younger than that for women. The authors reported that 22% of deaths were at ages less than 50 at death, compared with 9% for the general population. The median age at

death was lower for more severe degrees of learning disability, being 67.5 for mild, 64 for moderate, 59 for severe and 46 for profound learning disability.

The overview panel was able to reach agreement about the question of prematurity for 96% of the deaths of people with learning disability, and 42% of deaths were judged to be premature. The most common reasons were delays or problems with diagnosis or treatment and problems with identifying needs and providing appropriate care in response to changing needs.

The most common certified, underlying causes of death were heart and circulatory disorders (22%) and cancer (20%). These were also the two most common causes in the general population at the time in whom they accounted for 29% and 30% of deaths respectively. Almost half (49%) of deaths were at ages and from causes categorised by the methods adopted by the Office for National Statistics as potentially avoidable. This is twice the proportion (23%) seen in general population deaths in England at the time².

NHS England has now commissioned a continuing Learning disabilities mortality review programme to monitor deaths in people with learning disabilities (the LeDeR programme, run by the same team as the Confidential Inquiry). At the time of writing the programme is establishing processes, procedures and local contacts, working regionally, starting in the North of England. It now forms part of the Clinical outcomes review programme. Their strategy involves supporting the development of local review functions around the country, providing guidance on methods and collating and reporting the findings. Full details are on the review programme website³.

The Mazars report

In December 2015, the advisory and accountancy firm Mazars published an NHS England commissioned report into the deaths of people with learning disability or mental health problems in contact with Southern Health NHS Foundation Trust in the four years to March 2015. This was one of several investigations triggered by the death of Connor Sparrowhawk, an 18 year-old man with learning disabilities and autism who drowned in an assessment and treatment unit in 2013.

The report focussed mainly on the trust's procedures for identifying and investigating serious incidents and their use of statistical and contextual data to make sense of these. It looked particularly at the attention paid by the trust board and the CCGs commissioning care from the trust into the processes and findings of investigations.

Mazars noted that many investigations were of poor quality and took too long to complete. They considered that there was a lack of leadership, focus and sufficient time spent in the trust on carefully reporting and investigating deaths. They felt there was a

lack of family involvement in investigations after a death and considered that opportunities for the trust to learn and improve were missed.

They produced many recommendations for the trust and their commissioners, but also some relating to a national perspective on monitoring and learning from mortality patterns. Some of these related to the need to clarify definitions relating to which deaths should be investigated and to what extent. Others related to the need for more national work in facilitating the production of national mortality benchmarks for NHS organisations providing care for people with learning disabilities or mental health problems. This is a complex area as trusts provide different combinations of types of service to varied groups of patients. Overall death rates for providers would be expected to vary in relation to the type of work they undertake and the levels of need, dependency and frailty of the service users they look after.

Death certification data

Each year around 450,000 deaths are reported in England. About 1,000 death certificates indicate that the deceased person had learning disabilities. In some cases this is stated directly, in others an indicative diagnosis such as Down's syndrome is recorded. An early Improving Health and Lives report analysed death certificates in detail³. This drew attention to the substantially reduced age at death, the different age at death profiles for groups of people with different causes for their learning disability, and the contribution of a small number of specific important causes, notably epilepsy and aspiration pneumonitis.

Death certificate data has several drawbacks for monitoring mortality in people with learning disabilities. They miss a lot, probably selectively, and corresponding population data are not available. A reasonable estimate (discussed further below) is that there would be more than 3,000 deaths per year of people whose GPs identify them as having learning disabilities. So death certificates clearly give an incomplete picture even for this group (for example, most adults identified as having a learning disability in education services are not identified as such by services in adulthood, see Chapter 2). This is not surprising since they do not ask for a comprehensive list of conditions experienced by the deceased, only those that, in the opinion of the certifying doctor or coroner, formed part of the causal chain leading to death or were otherwise 'significant' to the cause of death. At present we do not have reliable local estimates of the age and sex breakdown for local populations of people with learning disability. This means that even if we did have complete accounts of the number of deaths amongst them we would not be able to calculate age adjusted death rates for comparison with local populations.

However, death certificate data are published regularly and collected through a well established and largely unchanging process. This makes them potentially valuable as a

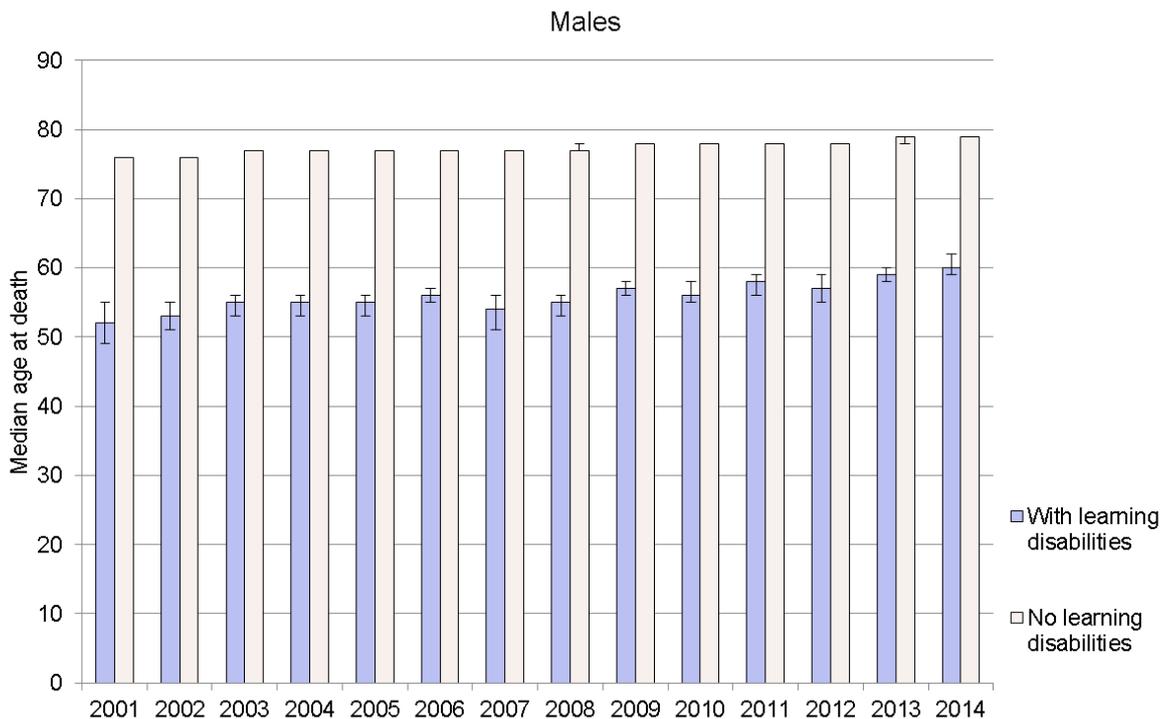
source of long-term trend data. In view of the lack of corresponding population data, the best way to use death certificates to compare mortality in people with learning disabilities with that in the general population is to compare ages at death.

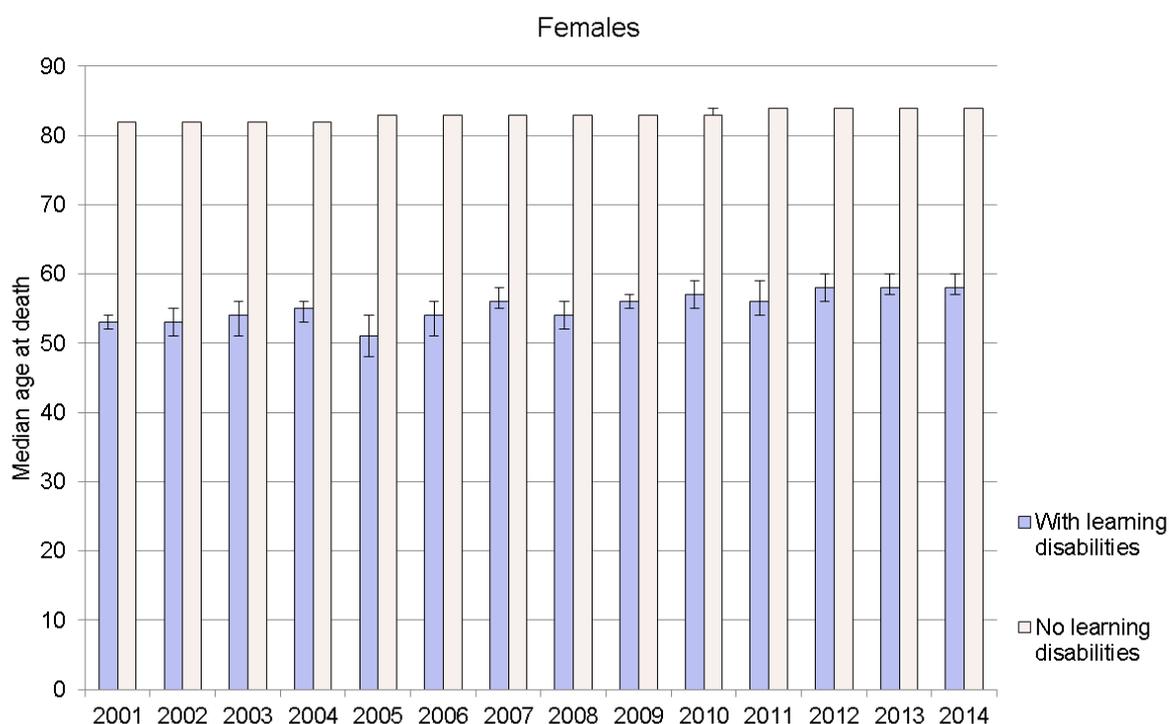
Figure 3.1 shows the trend in the median age at death. This is the middle of the distribution of the ages of all those dying; half died younger, half older. For men with learning disabilities, the median age at death has risen from 52 years in 2001 to 60 in 2014. For women it has risen from 53 to 58. The median age at death has also risen over this period for people without learning disabilities, but not by so much (for men from 76 to 79 years and for women from 82 to 84). Thus the gap in expectation of life by this measure has fallen from 24 to 19 years for men with learning disabilities and from 29 to 26 years for women.

It is not easy to attribute this improvement to any specific cause. It seems to have been fairly continuous through the period. A closer inspection of the data shows that the largest changes for people with learning disabilities have been decreases in the proportion dying between the ages of 50 and 59 and increases in the proportions dying between 60 and 69.

Figure 3.1. Median age at death recorded on death certificates in England for people dying in the years 2001 to 2014 categorised by whether or not the death certificate identified deceased as having a learning disability.

Bars indicate 95% confidence intervals.





National mortality study of people with learning disabilities

In 2015/16 the Learning Disabilities Observatory team collaborated with the national Learning disability mortality review (LeDeR) programme and the Medicines and Healthcare products regulatory authority (MHRA) on a study of mortality in people with learning disability. This was funded by the Department of Health. We used the Clinical practice research datalink (CPRD), a data source collated and managed by MHRA. This is a database of anonymized records of all the clinical and administrative transactions from several hundred general practices around England. The GP data are linked to death certificate data, routinely collected hospital admission statistical records and other national health data sources to produce comprehensive records about the health and healthcare of a large number of individuals.

For this study we looked at death rates and certified causes of death for all the individuals in the database, classifying people as having or not having a learning disability on the basis of diagnoses recorded by their GPs. We used data from a four year period, April 2010 to March 2014. The source was able to provide data about the numbers of people under the care of participating practices and death certification data for any who died in the period. This allowed us to calculate both overall death statistics and rates of deaths from specific underlying causes for a large population in a recent time period. The study identified 664 deaths in just under 60,000 person years' observation of people with learning disabilities. We estimate that the dataset covers a little more than 5% of the population of England.

The two key overall measures of mortality we used were the standardised mortality ratio (SMR) and life expectancy. The SMR is a ratio of the numbers of deaths observed in a group of people compared to the numbers expected if they had the same age and sex-specific death rates as the general population. The population of people with learning disabilities is younger and more dominantly male than the general population so it is important to make allowance for these characteristics in evaluating the number of deaths seen. Life expectancy is calculated from age-specific death rates and is an estimate of the average number of years a person would live if they experienced the current rates at each stage of their life.

People with learning disabilities had an SMR of 3.18 (95% confidence interval (CI) 2.94 to 3.43); that is the number of deaths was a little more than three times the number expected for a group of their size and age/sex composition. It was higher for women with learning disabilities (3.40 - 95% CI 3.02 to 3.81) than for men (3.03 - 95% CI 2.73 to 3.35). Life expectancy at birth for people with learning disabilities was 65.5 years (95% CI 61.9 to 69.2), 66.7 (95% CI 63.4 to 70.0) for women and 63.8 years (95% CI 57.7 to 69.9) for men. Compared to people without learning disabilities, this represents a shortfall in life expectancy of 19.7 years overall, 20.2 years for women and 19.7 for men.

The three most common causes of death for people with learning disabilities were circulatory diseases (22.9% of deaths), respiratory diseases (17.1%) and neoplasms (cancers) (13.1%). In comparison to what would be expected from general population death rates, there were 2.8 times the expected number of deaths from circulatory diseases and 4.9 times the number of deaths from respiratory diseases. The number of cancer deaths was close to the expected figure, although the profile of cancer types was distinctly different with an unexpectedly high number of deaths from colorectal cancer. Potentially preventable causes included epilepsy (3.9% of deaths) and aspiration pneumonitis (3.6% of deaths). These figures are set out in more detail in a forthcoming Public Health England factsheet and paper.

Future monitoring

The CPRD study provides useful and representative data for England as a whole. However it cannot provide information about local variations in mortality, mainly because the numbers are too small. We are currently working on a new study, the Learning Disability Health and Care programme. This is obtaining very detailed but anonymised grouped data from general practices at CCG level. In addition to a wide range of other data about health and health care, this should document the numbers of people with learning disabilities and the number of deaths for each CCG, giving detailed age and sex breakdowns for each. At the time of writing, details of the first year's data are not yet available. However, we anticipate that in the short term these should permit at least some analysis of overall death rates at some sub-national levels.

There is an urgent need to establish a national method of monitoring excess mortality for people with learning disability. The scale of this excess is now clear from our CPRD study. Addressing this requires local areas to have some nationally comparable indication of how well or badly they are doing and whether any particular conditions seem to be of particular importance in their areas. The health and care programme will provide a helpful start to this but will only provide overall rates, not details of causes.

Health services

This chapter summarises the information available from a range of published sources about the use of healthcare by people with learning disabilities. It begins with the coverage of annual health checks for people with learning disabilities. It goes on to explore use of secondary care services for physical health problems. Finally it looks at care by specialist learning disability services. These have a particular focus on mental and behavioural healthcare.

We have managed to obtain a wider range of data for this year's report. In some cases, particularly in-patient mental and behavioural healthcare, there is information about key issues from more than one source and asking slightly different questions. Where these appear to differ, rather than attempting to determine a single 'correct' version, we have presented all versions along with commentary intended to explain the differing perspectives. Care activities inevitably appear different from different vantage points. This can indicate important aspects of how they are delivered and managed. More detailed data tables are available in the accompanying data tables report, and most of the sources described in this chapter, particularly the censuses and the commissioning data, have been reported in detail elsewhere. Interested readers should consult the sources referenced.

Learning disability health checks

People with learning disabilities have more difficulty than others identifying ordinary health problems and getting treatment for them. As a response to this, annual learning disability health checks have been a key part of NHS plans to improve health and reduce premature mortality since 2008.

In 2014 to 2015, the learning disabilities health check programme was expanded from covering only adults aged 18 or over to include young people aged 14 to 17. This coincided with the expansion of the scope of the GP Quality and Outcomes framework (QOF) learning disability registers noted above.

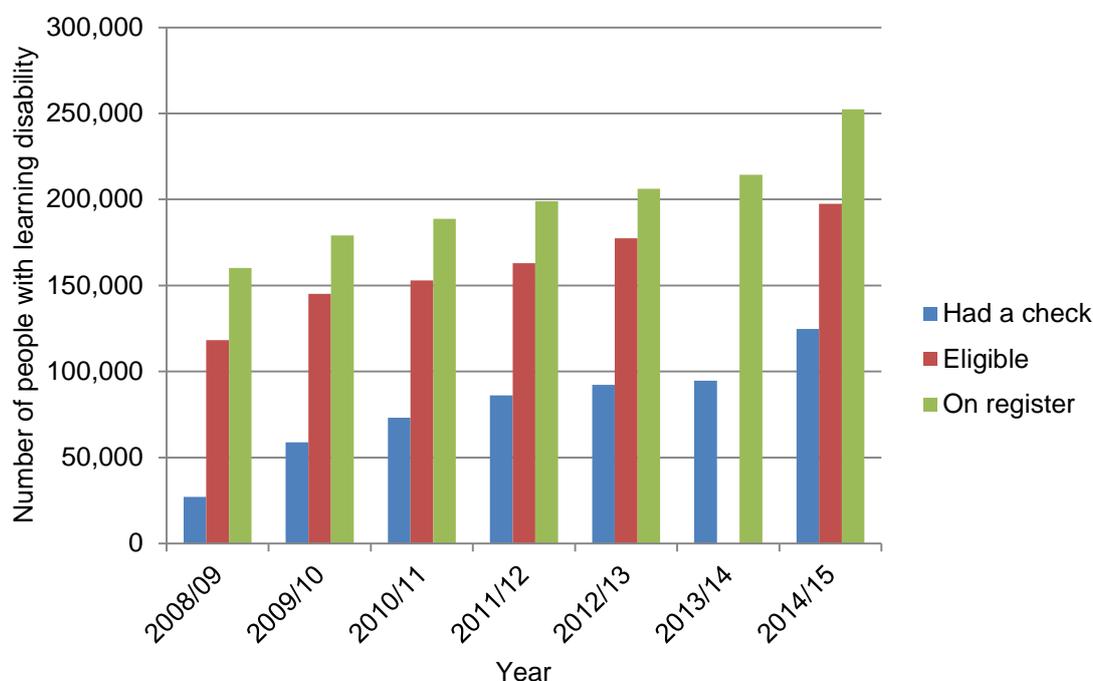
The data collection process has changed over the years but since April 2013 individual GP practices have been responsible for recording the data. This is collected from them by NHS Digital in an automated process. In 2014 to 2015, data was collected about the number of people eligible for a learning disability health check, the number of checks done and whether or not health action plans were created.

This chapter provides only a brief summary of the coverage of learning disability health checks and participation of general practices in the scheme. Further analysis and commentary was provided in a recent factsheet¹.

In 2014 to 2015, practices reported that there were 197,451 patients eligible for a learning disability health check (registered with their GP as having a learning disability and aged 14 or older). They reported that 124,785 checks were done, which gives an overall apparent coverage figure of 63.2%.

Figure 4.1 compares these figures with coverage rates in earlier years (see data tables report Table 4.1 for details). Changes to the scheme and the data collection processes over the years make year-on-year comparisons difficult but the key observation is that this year's number of checks is the highest so far.

Figure 4.1. Time trends in the number of learning disability health checks performed, the number of people eligible and the number on GP learning disability registers



The number reported as eligible for a learning disability health check was lower than expected. This year's data collection also included the number of people on a learning disability register aged 14 and over (total for England 239,244), which gives the lower estimate of 52.2% for the coverage.

General hospital services

People with learning disabilities use general hospital in-patient care for a wide range of physical conditions. In many cases conditions underlying their learning disability, such as Down's syndrome or cerebral palsy, have additional physical complications which necessitate extensive hospital in-patient care. Care of people with learning disabilities

who are admitted to hospital may be complicated in many ways. They may have relatively little capacity to understand what is happening to them or why. They may become confused or frightened by unfamiliar surroundings, or simply not understand what they are being asked to do. Staff may not always recognise that people have learning disabilities and they may not have been told this. In these cases some staff are not good at judging the extent to which patients understand what they are being told or asked and may mistake incomprehension for un-cooperativeness. There may be uncertainty over patients' capacity to consent to interventions and a lack of understanding of the legal requirements for proxy decision making if they cannot.

In the past, statistical data about the exact extent of in-patient care provided to people with learning disability has been lacking. Hospital episode statistics records do not routinely ask whether individuals being treated have disabilities. Disabilities can be recorded as comorbid diagnoses if clinicians choose but there is no requirement for negative statements that patients do not have disabilities. Exploratory studies undertaken by the Learning Disabilities Observatory indicated that recording of learning disability in this context is inconsistent, even for individuals treated repeatedly in the same hospital, and thus presumably very incomplete overall. Detailed age/sex specific information about the size of the population of people with learning disability for whom individual hospitals are providing care is also not readily available in most places.

This year, we were able to study the extent of use of hospital in-patient care for people with learning disabilities systematically as part of the work we undertook in collaboration with the Medicines and Healthcare Products Regulatory Agency using the Clinical practice research datalink (CPRD). We have outlined this data source and the study in Chapter 3 describing findings in relation to mortality.

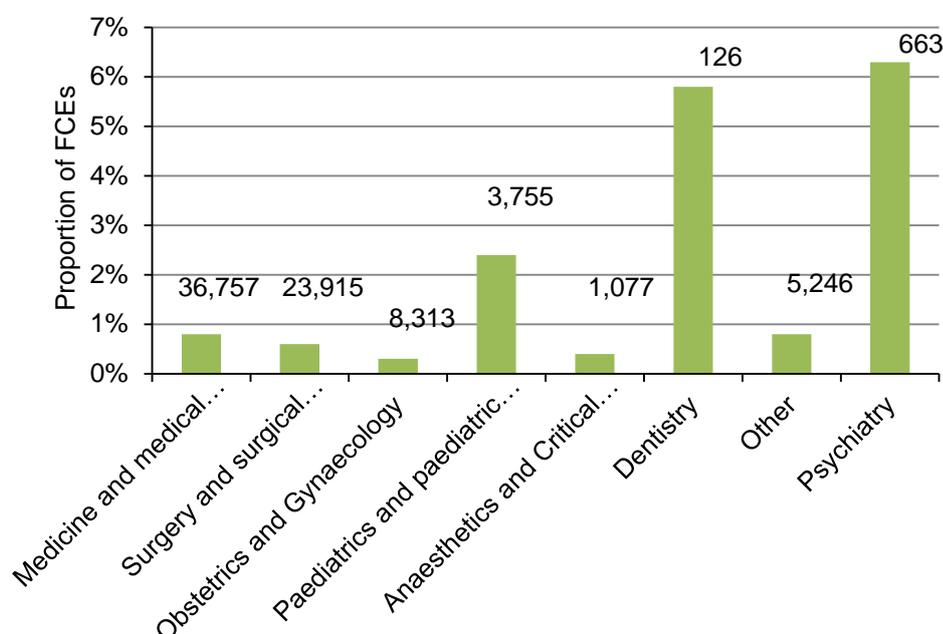
The CPRD provided details about all the care provided to patients registered with a group of anonymous general practices over a period of four years. This provided data on roughly 11.16 million person years experience of healthcare, following on average 2.8 million people over four years; roughly 5% of the population of England. The patients registered with participating practices included on average just under 15,000 with a learning disability. All hospitalisations in the whole group followed were identified from linked hospital admission records which indicated the specialty and duration of admissions and the numbers which were for conditions which should usually be avoidable through good primary care and personal social care. The study identified both people registered as having a learning disability by their GP and a further group (roughly an additional 10%) whose GP had recorded diagnoses clearly indicating learning disabilities. It covered hospital admissions in the four years from April 2010 to March 2014.

Overall, people identified as having a learning disability comprised 0.53% of the patients registered with their GPs. Figure 4.2 shows the proportion of finished consultant

episodes they used (see data tables report Table 4.2 for details and similar data for average bed occupancy). The chart is ordered from left to right starting with the specialties or specialty groups with the highest number of finished consultant episodes overall. Psychiatric specialties are reported separately.

In the two numerically largest specialties, medicine and surgery, people with learning disabilities used highly significantly more hospital care than others. The only substantial exception was obstetrics and gynaecology, where their use was lower than their proportion in the population. Three specialties, paediatrics, dentistry and psychiatry, stand out as areas where the numbers of both care episodes and bed days used by people with learning disabilities far exceeded their proportion in the population. In the case of paediatrics, the proportion does not substantially exceed the proportion of children identified as having learning disabilities by teachers and may reflect partly the more detailed attention to developmental assessment which is an integral part of the specialty. The high proportion of in-patient dental work presumably reflects the common use of general anaesthesia for procedures normally done under local anaesthetics in dental surgeries.

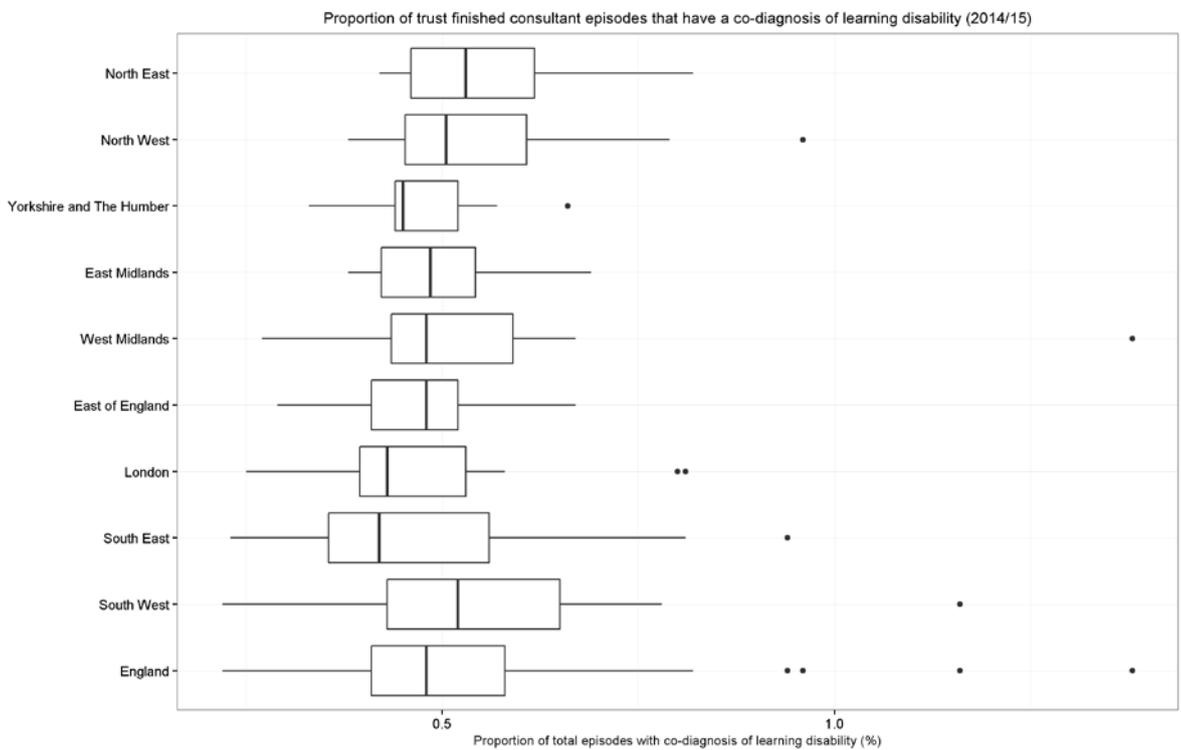
Figure 4.2. Proportion of Finished Consultant Episodes (FCEs) used by people identified by GP as having learning disabilities, by medical specialty, 2010 to 2011, to 2013 to 2014. The number above each bar is the total number of FCEs per 250,000 population per year.



The hospital episode statistics (HES) database includes details of all admissions, out-patient appointments and A&E attendances at NHS hospitals in England. We used HES data from 2014/15 to undertake a regional comparison of the proportion of episodes of care in acute trusts that had a diagnosis of learning disability recorded in the notes. The

regional medians ranged from 0.42% in the South East to 0.53% in the North East, although Figure 4.3 shows that there was substantial variation among acute trusts within each region.

Figure 4.3. The median proportion of episodes of care in acute hospital trusts that have a diagnosis of learning disability recorded in the notes, by former government region. The vertical line in the middle of each box is the median (middle) value for the acute hospital trusts in that region. The box contains half of all the trust values for the region. The lines represent the range of values in the region, unless there is an unusually high or low outlier, in which case this is represented by a dot.



Mental health care

People with learning disabilities are involved with mental health services in three ways. They may be referred for assessment of abilities and for assistance with speech and language development or daily living skills, for assessment or treatment of mental health problems or as a result of challenging behaviours. The nature of the underlying problem may not be clear at the point of referral. People with learning disabilities have substantially higher rates of major mental health problems and dementia than other people and also higher rates of common mental disorders such as anxiety and depression. Challenging behaviours may indicate difficulty communicating unhappiness or boredom, sometimes of a profound intensity. But they may also be symptomatic of a major mental health problem or may in some cases reflect more innate phenomena characteristic of some syndromes causing learning disability. Aggressive or destructive

behaviours are those most commonly discussed but repetitive stereotyped behaviours and self-destructive behaviours are also often substantial issues.

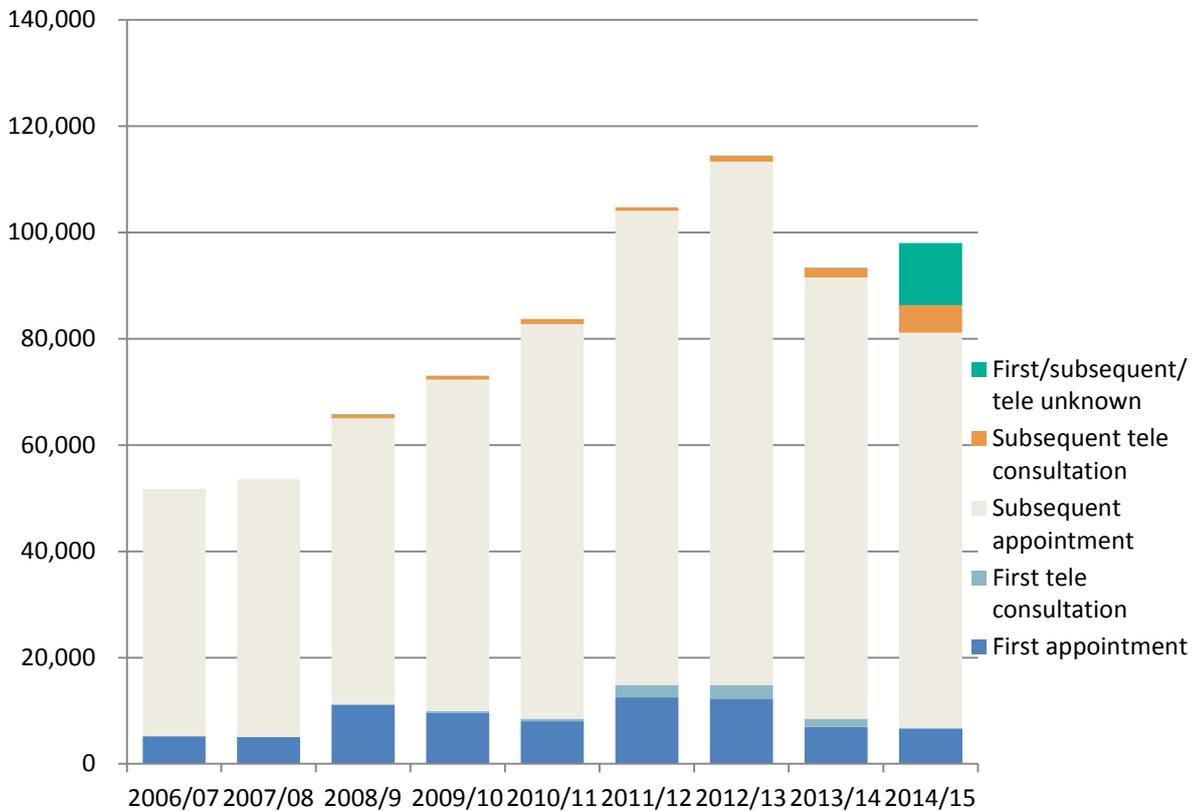
The contacts people with learning disabilities have with mental health services take many forms ranging from clinic attendances to long-term secure hospitalisation. Historically, many people with learning disabilities were accommodated in long-term hospital placements. The process of de-institutionalisation started in the 1980s, has continued until recent times and is, as yet, incomplete. Following revelations about the extent of abuse of patients at a private sector mental hospital, Winterbourne View, there has been a renewed impetus to identify the numbers of people with learning disabilities still living indefinitely in hospitals and to resettle these people in proper community based residential settings.

The statistical data about mental health care for people with learning disabilities has expanded greatly over the last three years as a result of initiatives arising from the Winterbourne View investigations. Two data sources have been available for many years. These document out-patient consultations and hospital in-patient episodes in NHS hospitals under the clinical specialty of psychiatry of learning disabilities. More recently, three new data sources have been added. Two relate specifically to care for people in psychiatric in-patient units. These are the annual psychiatric census and the Assuring Transformation data set reported by commissioners. The third is the mental health and learning disabilities dataset. This covers both in-patient and all forms of ambulatory care provided by mental health services, giving a patient centred perspective. Although private psychiatric hospitals undertaking work for the NHS are supposed to report to this dataset, they do not appear in currently published data.

Out-patient mental health care

Numbers of out-patient attendances under the specialty of psychiatry of learning disabilities are documented in out-patient hospital episode statistics (Figure 4.4). Data are available in a reasonably consistent form from 2006 to 2007, through to 2014 to 2015. These show a steady growth in recorded attendances and a small but steady increase in the proportion of telephone contacts from the earliest year until 2012 to 2013. The pattern changed in 2013 to 2014 with an overall substantial reduction in numbers of both all and first out-patient attendances and a sharp rise in the proportion of contacts by telephone. In the most recent year there was a considerable increase in numbers of attendances for which the details of the sequencing and location were not available. The pattern of a step change in the graph followed by resumption of the upward trend is so marked as to suggest this is an artefact arising from the administrative changes in the health services in April 2013 rather than a real change.

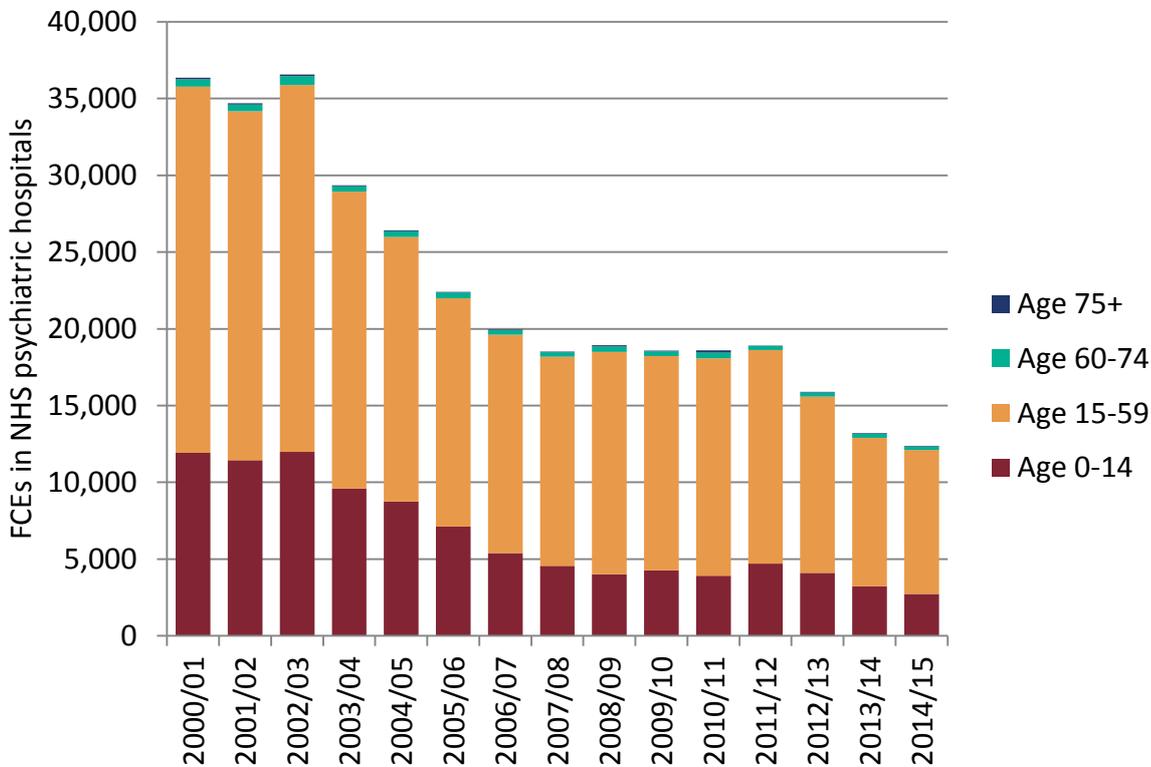
Figure 4.4. Out-patient attendances for psychiatry of learning disability, 2006 to 2007, to 2014 to 2015.



NHS in-patient mental health care

The trend in the amount of in-patient care in NHS hospitals can be shown for an even longer time frame from published sources. Figure 4.5 shows the annual numbers of consultant episodes. From an initial plateau of roughly 36,000 these dropped sharply between 2003 to 2004 and 2007 to 2008, the period of the main implementation of the recommendation of the government white paper ‘Valuing People’. Episode numbers steadied at around 19,000 per year until 2011 to 2012, the year in which the Winterbourne View scandal was uncovered. The last three years have seen further falls to just over 12,000 in 2014 to 2015. (Figure 4.5).

Figure 4.5. Finished Consultant Episodes in NHS Hospitals in the specialty of psychiatry of learning disabilities, 2000 to 2001, to 2014 to 2015.



The learning disability in-patient census

As investigations began in the aftermath of the Winterbourne View revelations it was apparent that NHS hospital episode statistics did not provide a comprehensive view of psychiatric in-patient care for people with learning disabilities. As large asylums closed a demand had arisen for care in low and medium secure facilities for which NHS acute psychiatric provision did not have the capacity. The gap was filled by private sector units. However, these new hospitals did not submit the normally required standard NHS data. Findings from a series of censuses of all psychiatric in-patient provision initiated by the Mental Health Act Commission in 2006 and continued until 2010 by its successor the Care Quality Commission suggested that, by 2010, out of a total of 3,642 current psychiatric in-patients with learning disability, 32.5% were in private hospitals with 45% of these being wards described as ‘long-stay’ or ‘rehabilitation’².

On the basis of this study, a series of three further annual censuses of in-patients in learning disability hospitals was commissioned. All providers of in-patient mental health services funded by the English NHS were asked to submit information on all publicly funded in-patients with learning disabilities and/or autism in their care at the end of the Septembers of 2013, 2014 and 2015³⁻⁵.

Taking these three reports together, the number of in-patients has reduced by 7.7%, from 3,250 in 2013 to 3,000 in 2015. There are substantial differences in the use of in-patient beds between parts of the country. Figure 4.6, using data from the third census (September 2015) shows the variation in rates of current in-patient psychiatric care for people with learning disabilities between the former government office regions. Residents in the North East were three times more likely to be receiving in-patient care than residents in the South West.

Figure 4.6. Current psychiatric hospitalisation rate for people with learning disabilities and/or autism, former government office regions. Source NHS Digital. Learning disabilities in-patient census, September 2015 and QOF learning disabilities register numbers March 2015. Error bars are 95% confidence intervals.



The three censuses give some impression of the extent to which the longer term patients are in fact being discharged. Published tables in the reports of the second and third census show the proportions of patients from the previous census who were in hospital a year later. Overall this was 61% of patients for both of the years spanned by the three censuses. However patients who had been in hospital longer in each of the first two censuses were more likely to be in hospital a year later. Thus, of patients who at each census had only been in hospital less than three months, 33% of those from the 2013 census and 34% from the 2014 census also appeared in the following census, but for patients who had been in hospital two years or longer, 73% and 72% were also

recorded in the subsequent year. A similar gradient was identified in relation to ward security. Of those in general (non-secure) psychiatric beds, from both the 2013 and the 2014 censuses, 45% were still in hospital a year later. However, for those in medium secure beds the figures were 79% and 81%.

Commissioner records of psychiatric in-patient care

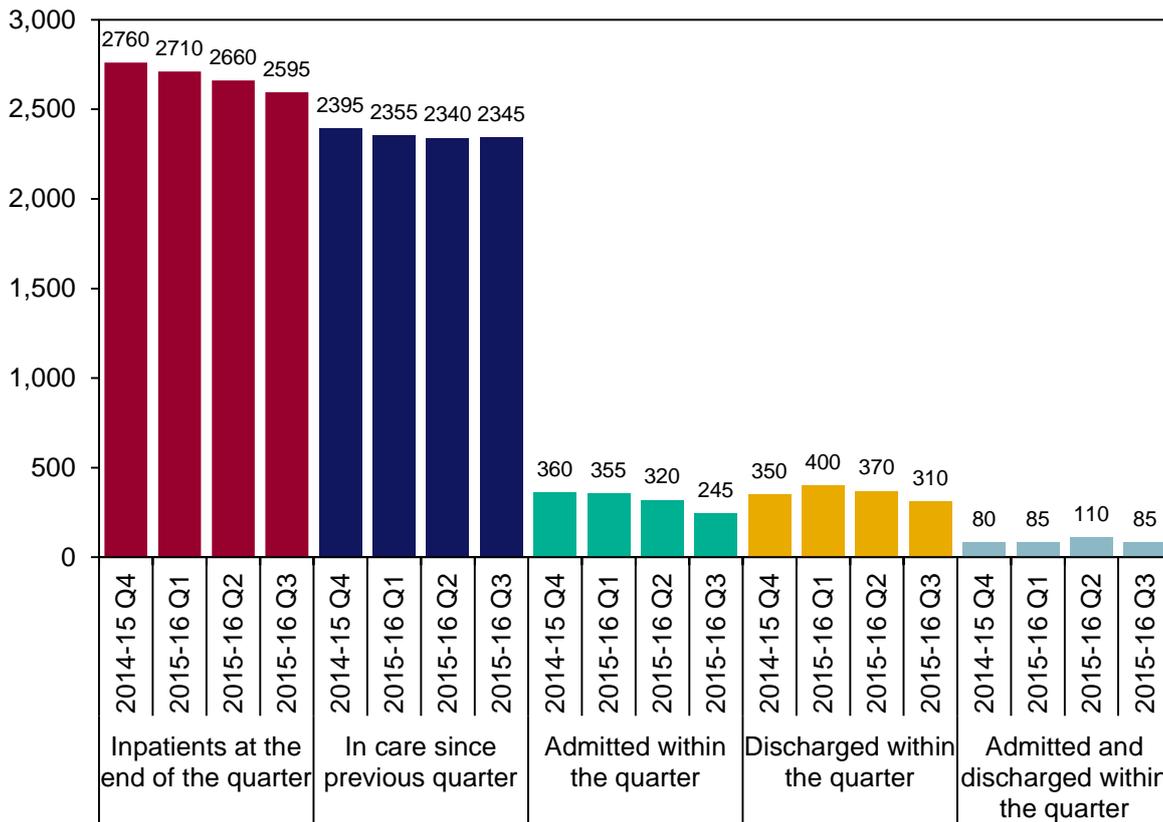
Psychiatric in-patient care for people with learning disabilities which happens for an extended period or in secure facilities is extremely expensive, as are alternative care arrangements for the individuals concerned. In the final report on the Winterbourne View scandal, the government committed to ensuring that ‘everyone inappropriately in hospital will move to community-based support as quickly as possible⁶.’ This is a large and complicated undertaking. In order to monitor progress, a new data collection from service commissioners was established. This monthly data return, called ‘Assuring Transformation’, was initially managed internally within NHS England. Since early in 2015 it has been collected by NHS Digital and data about the individuals reported is linked to corresponding learning disability in-patient census returns. Assuring Transformation returns report the numbers of people commissioners are commissioning care for. These comprise an account of the number of people in hospital, the numbers of admissions and discharges in the period, and information about the legal and administrative status and processes such as reviews and use of advocacy.

Commissioner returns have shown a consistently slightly smaller total number of in-patients than census returns. However detailed comparison work undertaken this year by NHS Digital has shown that the situation is more complex than simply some individuals being omitted from one collection. The Assuring Transformation return most closely aligned in time to the 2015 census identified 2,140 of the 3,000 patients in the census but a further 480 who were not. The census identified 855 patients not in the commissioning dataset. A small amount of these disparities arise from slight differences in scope. For example, patients in hospitals in England but commissioned by Scottish or Welsh health boards. NHS England and NHS Digital are currently working to clarify the position of the individuals identified in one but not both sources, the key aim being to ensure that appropriate reviews and care planning are provided for all relevant patients.

The greater frequency of the Assuring Transformation data means that this source can give a more detailed picture of how patterns of care are changing over time, although as commissioners can report retrospective data apparent changes in numbers over time can be difficult to interpret. In-patient care is commissioned broadly by two types of NHS organisation. General mental health in-patient care is commissioned by local clinical commissioning groups (CCGs) (46% of current in-patients). More secure care is commissioned by a smaller number of specialist commissioners with wider geographic responsibilities (54%). Numbers in beds commissioned by CCGs fell by 4.1% from the start to the end of 2015, numbers in specialist-commissioned beds by 4.5%. Figure 4.7

shows the patient flow statistics for each of the four quarters. These suggest that the decline reflects a reduction in admissions but also an increase early in the year of discharges. Monthly and quarterly reports from Assuring Transformation provide more detail on these and many other areas.

Figure 4.7. Number and flow of people with learning disabilities and/or autism in in-patient learning disability or mental health services, January to December 2015



Specialist secondary learning disability services

The mental health and learning disabilities dataset is a national dataset documenting the packages of care individuals receive from specialist mental health services. As originally designed this did not cover services under the specialty of psychiatry of learning disabilities. However from October 2014, its scope was widened to include this group of patients. National tables are published each month showing activity for clinical commissioning group areas and provider units. Quarterly supplements support a wider range of geographies. As the inclusion of learning disability services is relatively recent a key concern is to explore how consistently these appear to be being submitted.

Six indicators specific to people being cared for under learning disability services are published regularly: numbers in touch with services, numbers with a current open

referral, numbers with a current ward stay, and three indicators relating to numbers restricted in various ways under the Mental Health Act.

Figure 4.8. The median monthly proportion of people on a GP learning disability register in a given local authority in contact with their local NHS learning disability services, by former government region, October 2014 to September 2015.

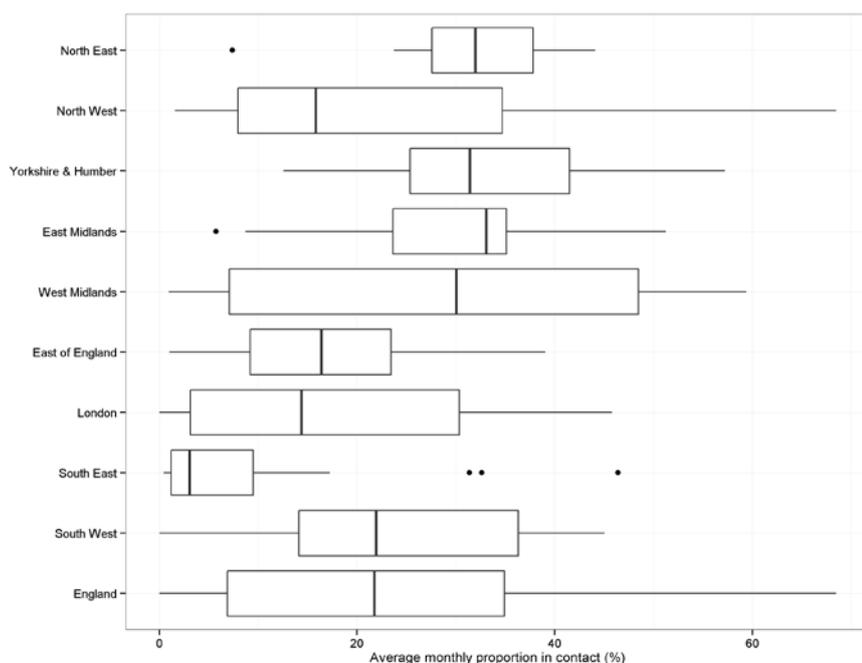


Figure 4.8 shows the wide range of rates of people with learning disabilities in contact with specialist secondary learning disability services in the first year of data collection. The data is summarised by region. The vertical line in the middle of each box is the median (middle) value for the local authorities in that region. The box contains half of all the local authority values for the region. The lines represent the range of values in the region, unless there is an unusually high or low outlier, in which case this is represented by a dot.

The region with the lowest median proportion of people in contact with their local NHS learning disability services was the South East (3.1%). Four regions had markedly higher median proportions in contact with NHS learning disability services, namely the West Midlands (30.1%), Yorkshire & Humber (31.4%), North East (32.0%) and the East Midlands (33.1%). There was substantial variation among local authorities within each region as indicated by the wide lines on Figure 4.8. Some of the low figures may represent incomplete reporting.

Education

Information on the education of children with special educational needs (SEN) associated with learning disabilities is provided in a series of annual reports published by the Department for Education (DfE). The Special Educational Needs (Information) Act 2008 requires the Secretary of state for Education to publish information about pupils in England with SEN each calendar year in order to help improve the wellbeing of these pupils. This requirement has led to the publication between 2009 and 2014 of the annual series *Children with Special Educational Needs: An Analysis*.¹⁻⁶ In 2015, the format of this reporting changed to a summary report and extensive signposting of potential users to relevant source data⁷.

The primary source of information for reporting on SEN is the DfE's National pupil database. Children with SEN in this database are identified through the school census. This survey, undertaken each school term, collects information on all children enrolled in all English state funded schools and non-profit making independent special schools during that term. Schools have a statutory responsibility to return school census data under section 537A of the Education Act 1996.

Children not included in the school census include those being educated at home, in independent (non-state funded) mainstream schools or in for-profit independent special schools. It has been estimated that the school census includes information on approximately 97% of English children of statutory school age⁸.

Unless specified, 2014/15 information contained in this chapter is extracted from the statistical first releases *Schools, pupils and their characteristics: January 2015*⁹ and *Special Educational Needs in England: January 2015*.¹⁰

How many school children have learning disabilities?

The identification of SEN prior to 1 September 2014 was undertaken at three levels:

- School Action (extra or different help is provided to the child)
- School Action Plus (extra or different help is provided plus the class teacher and the school's special educational needs coordinator [SENCO] receive advice or support from outside specialists, eg specialist teachers, an educational psychologist, a speech and language therapist or other health professionals)
- statement of SEN (the pupil has a statement of SEN, a legal document that specifies the child's needs and the extra help they should receive)

All schools were obliged to provide information on the type of primary and, if relevant, secondary SEN for children at School Action Plus and children with a statement of SEN.

Three categories of SEN are associated with learning disability: moderate learning difficulty (MLD), severe learning difficulty (SLD) and profound multiple learning difficulty (PMLD).

The special educational needs and disability (SEND) provisions in the Children and Families Act 2014 were introduced on 1 September 2014. From that date, any child or young person who was newly referred to a local authority for assessment was considered under the new education, health and care (EHC) plan assessment process. The legal test of when a child or young person requires an actual EHC plan remained the same as that for a statement under the Education Act 1996. As such, information on children with a statement of SEN or an EHC plan should be comparable over time across the introduction of these legislative changes.

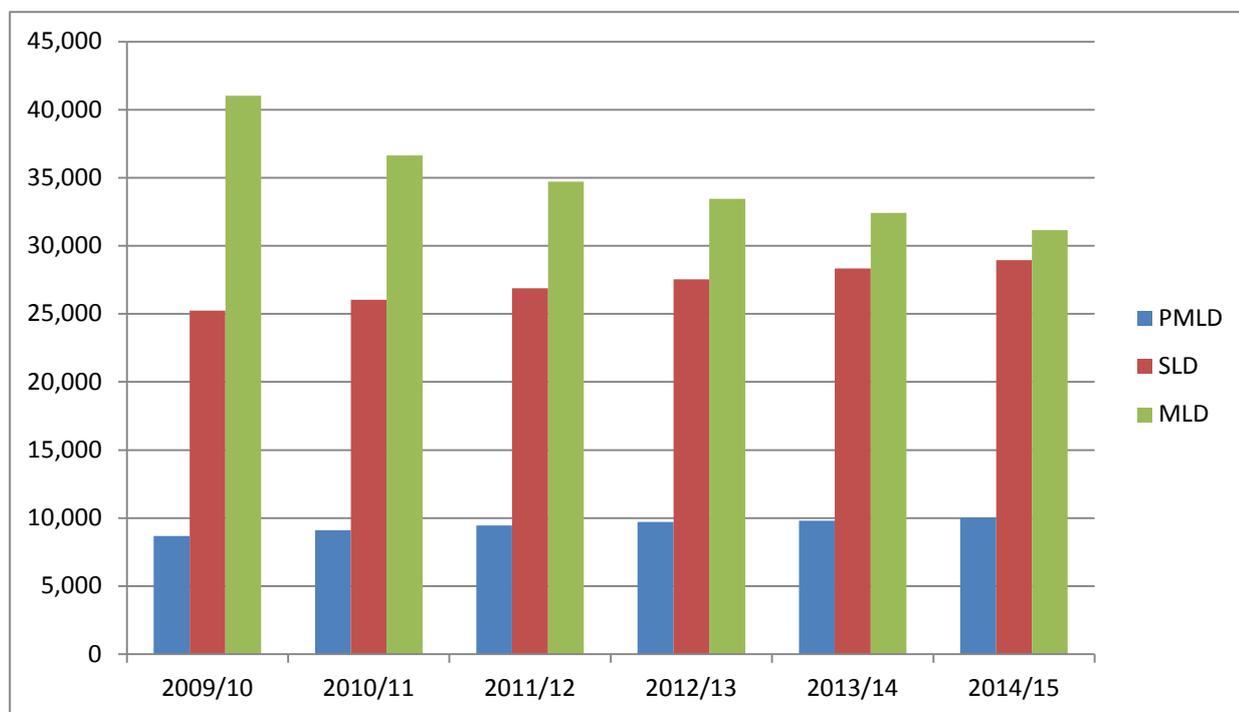
However, the SEND provisions in the Children and Families Act 2014 combined previous 'School Action' and 'School Action Plus' categories and replaced them with a new category 'SEN support'. Information on type of SEN for all children on SEN support was collected from January 2015. As a result, information on children with a SEN who do not have a statement or an EHC plan will not be comparable over time across the introduction of these legislative changes.

Varying time periods have been allowed to make the transition between the old and new systems:

- transfers to SEN Support for those currently at school action or school action plus must be completed by Summer 2015
- transfers to EHC plans for those that currently have a statement of SEN must be complete by Spring 2018

Figure 5.1 (for further details see Table 5.1 in the separate data tables report) shows the number of children with a statement of SEN or an EHC plan and a primary SEN associated with learning disabilities in state funded primary, secondary and special schools and non-maintained special schools in England from 2009/10 to 2014/15.

Figure 5.1: Number of children with a statement of SEN or an EHC plan and a primary SEN of moderate learning difficulty (MLD), severe learning difficulty (SLD) or profound multiple learning difficulty (PMLD) in state funded primary, secondary and special schools and non-maintained special schools in England 2009/10 to 2014/15



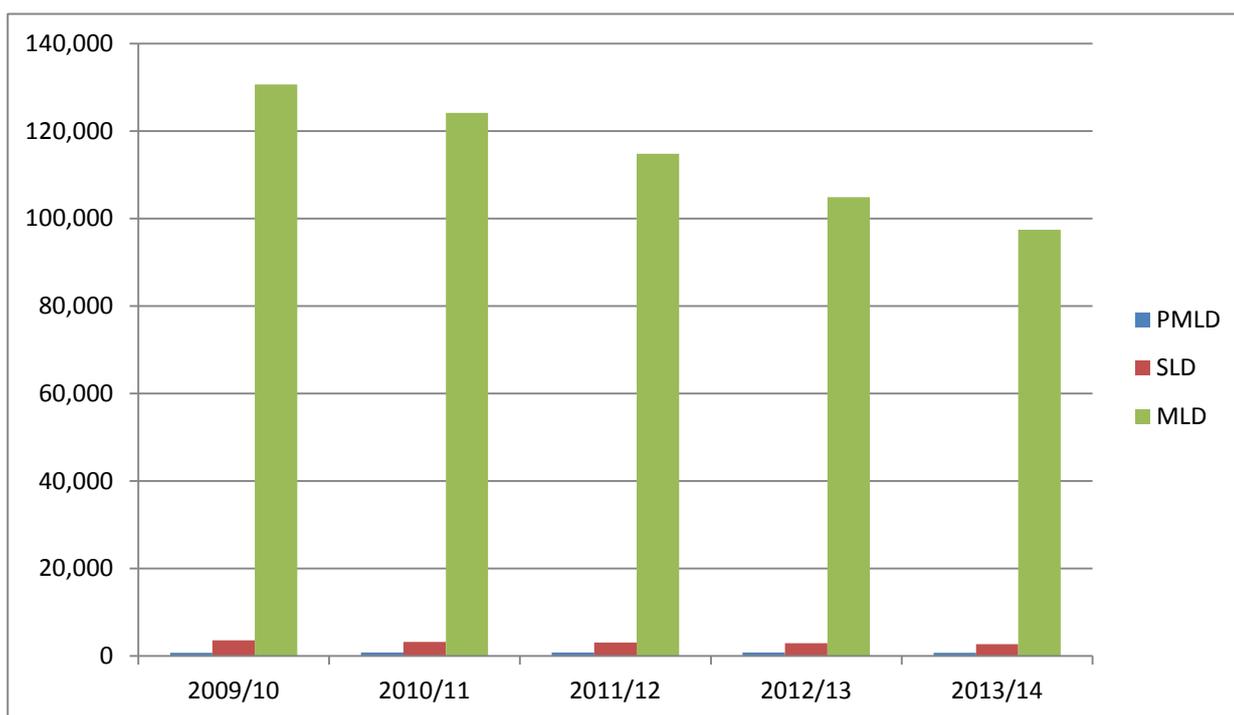
In 2014/15, 70,065 children in England had a statement of SEN or an EHC plan and were identified as having a primary SEN associated with learning disabilities. Of these, 44% were identified as having MLD, 41% SLD and 15% PMLD. Between 2009/10 and 2014/15, the number of children in England who had a statement of SEN or an EHC plan and were identified as having a primary SEN associated with learning disabilities reduced by 6.5%. This reduction was driven by a marked reduction in the number of children identified with MLD (24% over the period), attenuated by modest increases in the number of children identified with SLD (15% over the period) and PMLD (15% over the period).

Over the same time period, however, the total number of children on school rolls increased by 4.2%. As a result, the percentage of children with a Statement of SEN or an EHC plan who had a primary SEN associated with learning disabilities decreased from 0.93% in 2009/10 to 0.83% in 2014/15. As above, this reduction was driven by a reduction in the percentage of children identified with MLD from 0.51% in 2009/10 to 0.37% in 2014/15. The percentage of children identified with SLD and PMLD showed marginal increases over the same period (SLD 0.31% to 0.34%; PMLD 0.11% to 0.12%).

As noted above, the collection of information on children with SEN who do not have a statement/EHC plan is currently in a state of transition. Between 2009/10 and 2013/14, information on type of SEN was only collected for children at School Action Plus in the assessment of SEN, and not collected for children at the School Action stage. From 2015/16 information on type of SEN will be collected for children requiring SEN Support, a new category that combines the previous School Action Plus and School Action stages in the assessment of SEN. 2014/15 is a transitional year.

Figure 5.2 (for further details see Table 5.2) shows the number of children at School Action Plus who have a primary SEN associated with learning disabilities in state funded primary, secondary and special schools and non-maintained special schools in England from 2009/10 to 2013/14.

Figure 5.2: Number of children at School Action Plus and a primary SEN of moderate learning difficulty (MLD), severe learning difficulty (SLD) or profound multiple learning difficulty (PMLD) in state funded primary, secondary and special schools and non-maintained special schools in England 2009/10 to 2013/14



In 2013/14, 134,960 children in England were identified at the School Action Plus level and were identified as having a primary SEN associated with learning disabilities. Of these, 96% were identified as having MLD, 3% SLD and 1% PMLD. Between 2009/10 and 2013/14, the number of children in England at School Action Plus who were identified as having a primary SEN associated with learning disabilities reduced by 25%. This reduction was driven by a marked reduction in the number of children identified with MLD (25% over the period).

In 2014/15 214,025 children in England who were identified at School Action Plus/SEN support were identified as having a primary SEN associated with learning disabilities. Of these, 98% were identified as having MLD, 1% SLD and less than 1% PMLD. These figures are not directly comparable to 2013/14 figures.

Variation in the identification of learning disabilities among children

Gender

All forms of SEN associated with learning disabilities are more common among boys, reflected in the DfE statistics which report 4.4% of boys and 2.9% of girls being identified as having a primary SEN associated with learning disabilities (see Table 5.3). While these data are transitional due to the phased introduction of data collection on SEN type on children formerly at School Action, very similar associations with gender have been apparent in previous data releases.¹¹

Age

The association between child age and the identification of primary SEN (SEN Support and with statement/EHC plan) associated with learning disabilities is presented in Figures 5.3 to 5.5 among children aged 5-15 at the start of the academic year in 2015. Identification rates for SEN associated with learning disabilities are likely to be unreliable outside the age-band where schooling is compulsory as children may enrol early or stay on to later ages as a result of some types of disability (eg PMLD), and be more likely to leave at age 16 as a result of other types of disability (eg MLD).

Identification rates of MLD and SLD based on a child having a statement/EHC plan both show a gradual increase across the ages at which schooling is compulsory. For children with PMLD, however, rates decline over this period. The difference in these trends is probably related to the ease of identification of PMLD in young children and higher mortality rates among children with PMLD across childhood.

At all ages, the majority of children identified with SLD or PMLD have a statement/EHC plan. In contrast, the majority of children identified with MLD are identified at SEN support, which increases up to the transition point from primary to secondary school age then decreases to the age of 15 years.

Figure 5.3: Age-specific identification rate per 1,000 of children with a primary SEN of MLD at SEN support and with statement/EHC plan, 2015

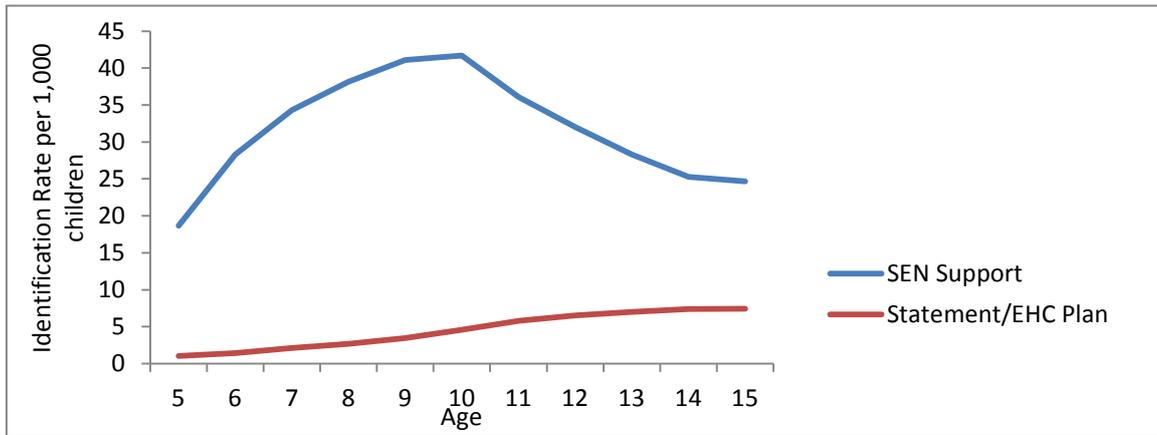


Figure 5.4: Age-specific identification rate per 1,000 of children with a primary SEN of SLD at SEN support and with statement/EHC plan, 2015

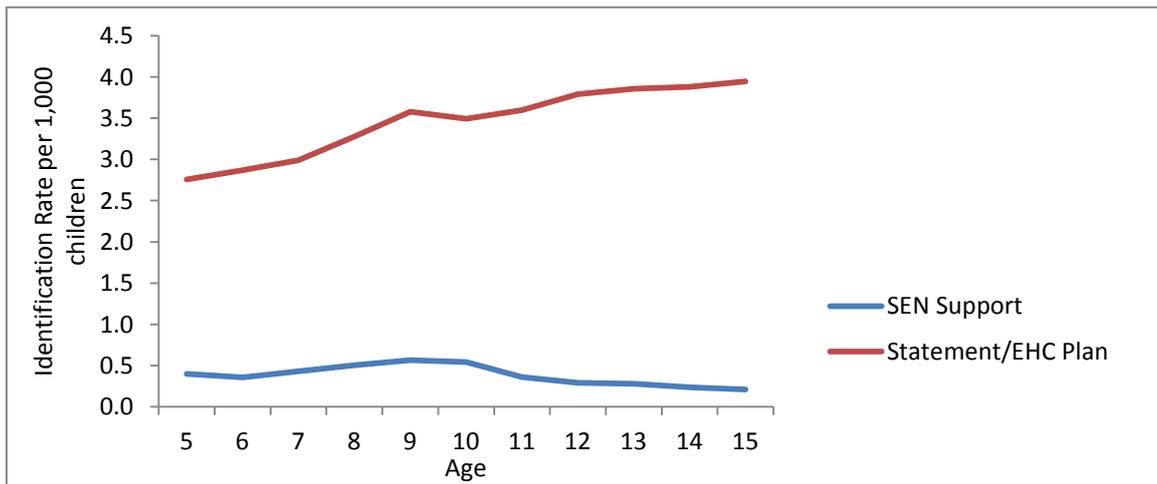
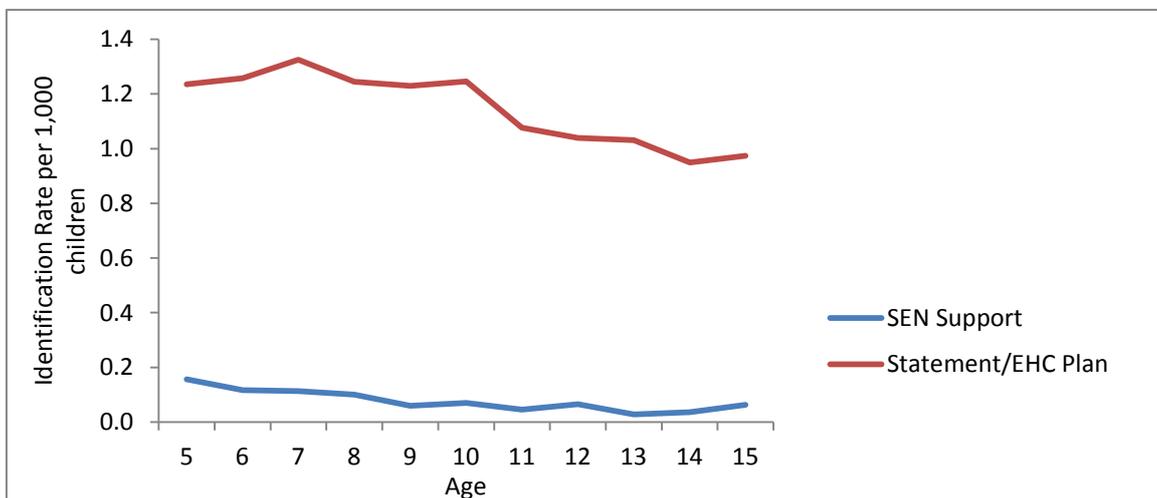


Figure 5.5: Age-specific identification rate per 1,000 of children with a primary SEN of PMLD at SEN support and with statement/EHC plan, 2015



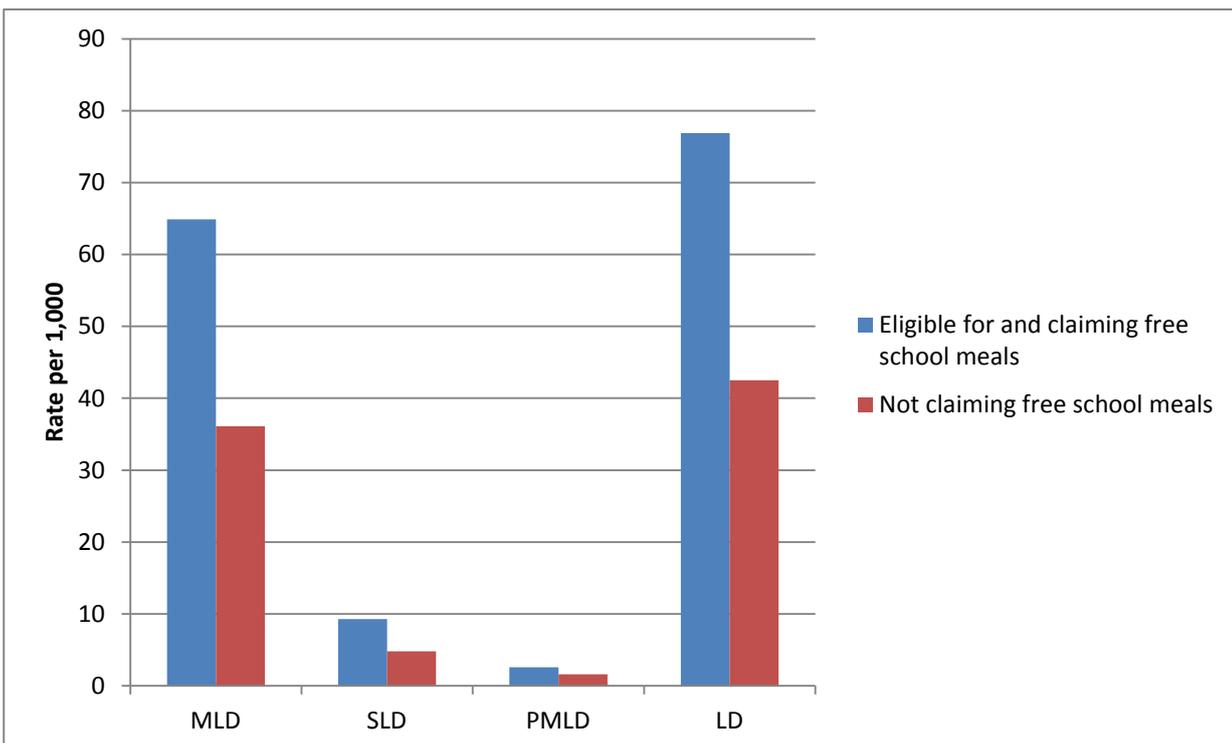
Poverty

Children from poorer households or who are living in more deprived neighbourhoods are more likely to be identified as having SEN associated with learning disabilities⁸. In January 2015, 15.2% of pupils of state funded schools were eligible for and claiming free school meals. In contrast, 31.4% of children at SEN support with SEN associated with learning disabilities and 35.6% of children with statements/EHC plans with SEN associated with learning disabilities were eligible for and claiming free school meals. These rates were elevated amongst all groups, and was highest among children with MLD (31.5% at SEN support, 37.8% with statements/EHC plans), compared to children with SLD (29.2% at SEN support, 35.5% with statements/EHC plans) and children with PMLD (23.6% at SEN support, 29.0% with statements/EHC plans).

Between 2000 and 2015 the percentage of pupils of state funded schools who were eligible for and claiming free school meals dropped from 16.2% to 15.2%. These rates rose among children with SEN associated with learning disabilities who had a statement/EHC plan (36.0% to 37.8% for children with MLD, 32.9% to 35.5% for children with SLD, 25.4% to 29.0% for children with PMLD).

Figure 5.6 shows identification rates of SEN associated with learning disabilities among children eligible for and claiming free school meals and other children for England in January 2015.

Figure 5.6: Identification rates of SEN per 1,000 children associated with learning disabilities among children by free school meal status, England, January 2015



Ethnicity

The identification of SEN associated with learning disabilities differs considerably between ethnic groups.⁸ Table 5.4 presents information on the prevalence of primary SEN associated with learning disabilities among children in England at SEN support or with a statement/EHC plan in 2015 by ethnicity.

Identification rates 25% or more above the national average were recorded among:

- traveller children of Irish heritage (for MLD, SLD and PMLD)
- children of Romany gypsy heritage (for MLD, SLD and PMLD)
- children of Pakistani heritage (for MLD, SLD and PMLD)
- children of Bangladeshi heritage (for PMLD)
- children of 'other' Asian heritage (for PMLD)
- children of black Caribbean heritage (for MLD)
- children of black African heritage (for PMLD)
- children of 'other' black heritage (for SLD and PMLD)
- children of 'other' 'mixed' heritage (for PMLD)

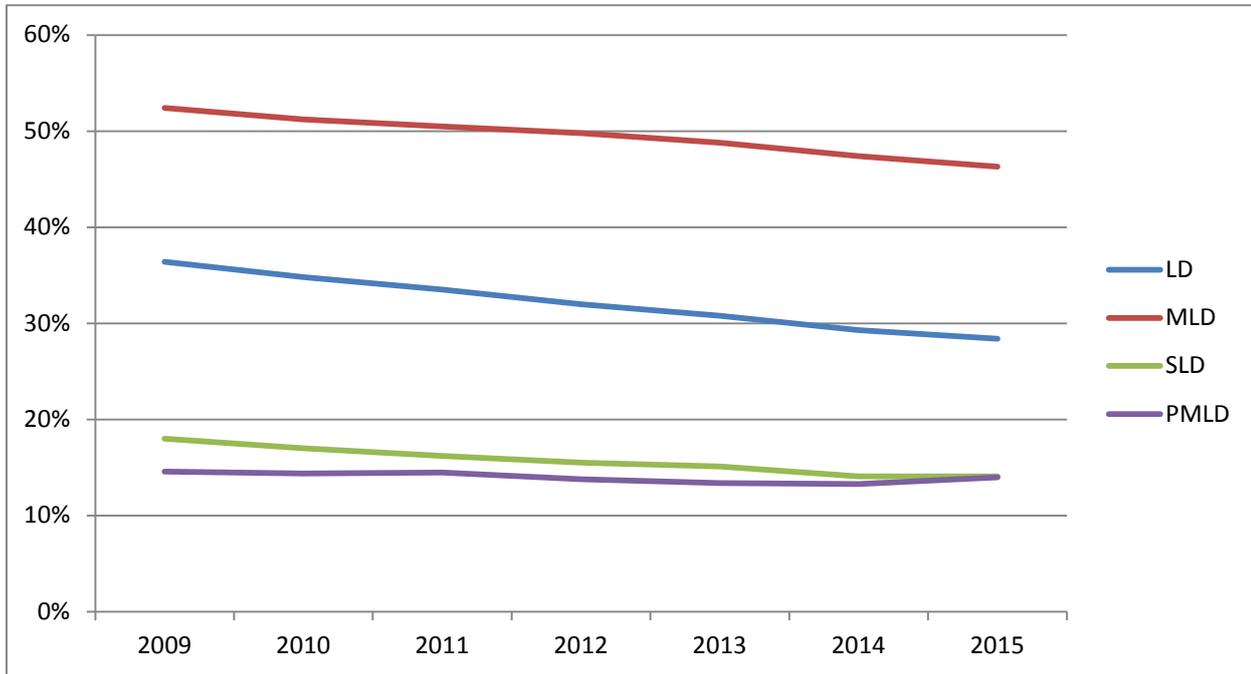
Education in mainstream schools

The 'Special educational needs in England' series contains information on the number of children with primary SEN associated with learning disabilities who are educated in mainstream and special schools (see Table 5.5).

In January 2015, 82% of children with a primary SEN (SEN support or with statement/EHC plan) associated with learning disabilities were being educated in mainstream schools. In contrast, 21% of children with a primary SEN of SLD and 19% of children with a primary SEN of PMLD were being educated in mainstream schools.

Between 2009 and 2015 the percentage of children with a statement/EHC plan and a primary SEN associated with learning disabilities being educated in mainstream schools reduced from 36% to 28% (Figure 5.7, Table 5.5). This was primarily accounted for by a reduction in the proportion of children with a primary SEN of MLD and SLD being educated in mainstream schools.

Figure 5.7: Percentage of children with a statement/EHC plan and primary SEN associated with learning disabilities being educated in a mainstream school, England 2009-2015



There was substantial variation across local authorities and regions in the percentage of children with a primary SEN associated with learning disabilities (SEN support or statement) who were being educated in mainstream schools.

For children with a primary SEN of MLD: the 10% of councils making most use of mainstream schools placed 99% or more of children with MLD in mainstream schools; the 10% of councils making least use of mainstream schools placed less than 86% of children with MLD in mainstream schools.

For children with a primary SEN of SLD: the 10% of councils making most use of mainstream schools placed 44% or more of children with SLD in mainstream schools; the 10% of councils making least use of mainstream schools placed less than 11% of children with SLD in mainstream schools.

For children with a primary SEN of PMLD: the 10% of councils making most use of mainstream schools placed 38% or more of children with PMLD in mainstream schools; the 10% of councils making least use of mainstream schools placed less than 6% of children with SLD in mainstream schools.

Absence and exclusion

The series 'Children with special educational needs' contained detailed information on the school attendance and exclusion of children with and without SEN nationally and, for some indicators, by Local Authority. For 2013/14, equivalent data are provided by Special educational needs: an analysis and summary of data sources⁷ and Absence and exclusions additional analysis for pupils with special educational needs (SEN).¹²

Absence

Absence from school is measured as the average percentage of half-day sessions throughout the year for which the child was absent. Absences are recorded as authorised or unauthorised:

- authorised absence involves permission from a teacher or other authorised representative of the school for absences for which a satisfactory explanation has been provided
- unauthorised absence includes all unexplained or unjustified absences. Arriving late for school, after the register has closed, is recorded as unauthorised absence.

Rates of overall, authorised and unauthorised absence for children with a primary SEN associated with learning disabilities are presented in Table 5.6. In 2013/14 (the latest year for which data are available) children with a primary SEN associated with learning disabilities were more likely than other children to be absent from school, with children with PMLD on average missing one in seven half-day sessions. In the majority of instances absences were authorised.

Reasons recorded for absences for children with a statement of SEN are presented in Table 5.7 for 2013/14 (the latest year for which data disaggregated by type of SEN are available). Illness and medical/dental appointments accounted for 57% of absences of children with MLD, 72% of absences of children with SLD and 78% of absences of children with PMLD.

Exclusion

Information is available on fixed period and permanent exclusions. A 'fixed period exclusion' is recorded when a child is excluded from a school but remains on the register (as they are expected to return once the exclusion period is over). A 'permanent exclusion' is recorded when a child is excluded from a school and their name removed from the register.

The percentages of children with primary SEN associated with learning disabilities who received one or more fixed term exclusions and who were permanently excluded within

each year is presented in Table 5.8 for the period up to 2013/14 (the latest year for which data disaggregated by type of SEN are available). Children with a primary SEN of MLD were markedly more likely to be excluded (fixed-term exclusion 4.9%; permanent exclusion 0.2%) than children with no SEN (fixed-term exclusion 1.5%; permanent exclusion 0.04%). Children with a primary SEN of PMLD were less likely to be excluded (fixed-term exclusion 0.3%; permanent exclusion figures not available as very low) than children with no SEN.

The reasons for fixed term and permanent exclusion in 2013/14 of pupils with primary SEN associated with learning disabilities are given in Table 5.9.

For children without SEN, the most common reasons for fixed term exclusions were persistent disruptive behaviour (22.7% of exclusions), physical assault against a pupil (21.0%), 'other' (19.7%) and verbal abuse/threatening behaviour against an adult (17.5%). For children with MLD, the most common reasons were similar: persistent disruptive behaviour (28.0%), physical assault against a pupil (18.5%), verbal abuse/threatening behaviour against an adult (18.4%) and 'other' (14.3%).

For children with SLD, the most common reasons for fixed term exclusions were physical assault against an adult (24.5%), persistent disruptive behaviour (23.5%), physical assault against a pupil (17.0%) and verbal abuse/threatening behaviour against a pupil (16.0%). The pattern for children with PMLD was similar: physical assault against an adult (29.7%), persistent disruptive behaviour (29.7%), physical assault against a pupil (23.4%) and verbal abuse/threatening behaviour against an adult (12.5%).

For children without SEN, the most common reasons for permanent exclusions were persistent disruptive behaviour (26.7% of exclusions), physical assault against a pupil (17.5%), 'other' (16.1%) and drug and alcohol related reasons (13.8%). For children with MLD the most common reasons were broadly similar: persistent disruptive behaviour (34.8%), physical assault against a pupil (18.1%), 'other' (14.1%) and physical assault against an adult (11.5%). The number of exclusions involving children with SLD (10 exclusions (rounded figure)) and children with PMLD (less than five exclusions) were too small to allow for meaningful analysis of the reasons for permanent exclusions.

Children's social care

The Department for Education collects information on children in need and looked after children.

Children in need

Information on children in need is provided in a series of Statistical First Releases Characteristics of children in need in England published by the Department for Education (DfE).¹⁻⁶ Under section 17 (10) of the Children Act 1989, a child is a child in need if:

- he/she is unlikely to achieve or maintain, or have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him/her of services by a local authority
- his/her health or development is likely to be significantly impaired, or further impaired, without the provision for him/her of such services, or
- he/she is a disabled child

These figures are used to monitor the workload and performance of local authority children's social care services, and to identify the number of children who are subject to safeguarding procedures. Children in need are those who have been referred to the local authority and have been assessed to be in need of services.

The Children in need data include a series of codes describing the nature of the child's disability (if they have one). Multiple disabilities can be coded including disability in 'learning'.

At 31 March 2015, 23,216 children in England were identified as being in need and to have a disability associated with learning. This represents 0.2% of the total child population in England (see Table 6.1). At all points in time (and in all regions) the prevalence of 'learning disability' identified in the Children in need census was markedly lower than: (1) the estimated prevalence of learning disabilities;⁷ (2) the prevalence of severe/profound learning difficulty recorded in the National pupil database; (3) the prevalence of learning disabilities among adults recorded by GPs and by Adult social services. Although the discrepancy with the National pupil database may be due to definitional differences between a 'disability associated with learning' and 'learning difficulties', discrepancies with figures from other sources cannot be readily accounted for.

The variation by local authority was substantial. At the lowest end, 10% of local authorities identified 0.08% or fewer children as being in need and having a disability

associated with learning. At the highest end, 10% of local authorities identified 0.36% or more children as being in need and having a disability associated with learning.

Looked after children

Information on 'looked after children' (or children in the care of the local authority) is provided in a series of Statistical first releases 'Outcomes for children looked after by local authorities in England' published by the Department for Education (DfE).⁸⁻¹³

Children may be 'looked after' by a local authority for a number of reasons. These include:

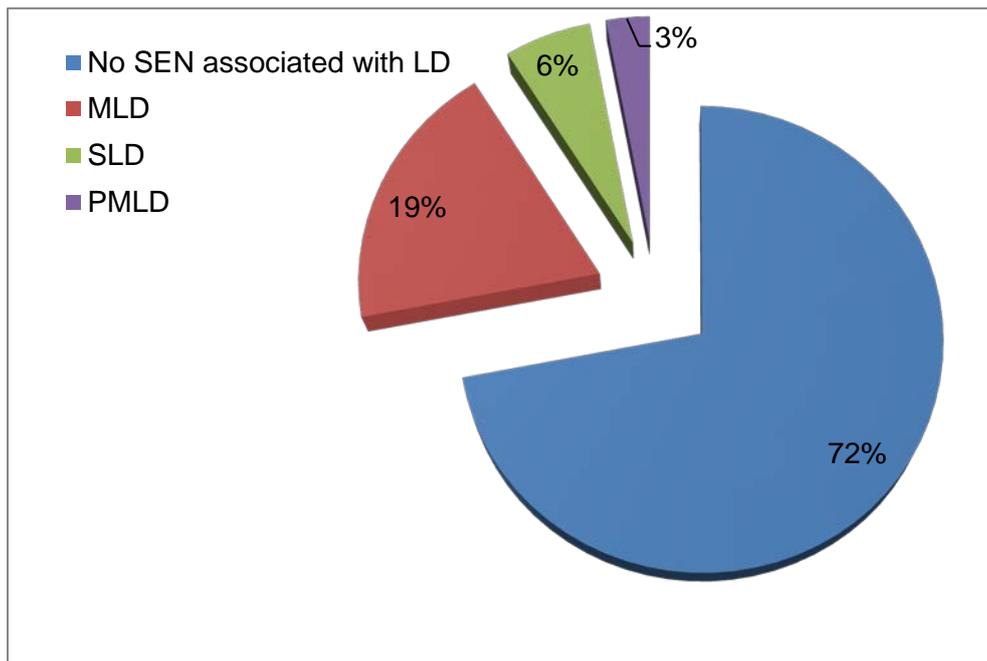
- all children who are subject to a care order, interim care order or emergency protection order under the Children Act, 1989 where the local authority has parental responsibility for that child
- children under a criminal law supervision order with a residence need to live in local authority accommodation
- children who have appeared in court and have been bailed to reside where the local authority directs - and are being provided with a local authority funded placement;
- children who are remanded to the local authority where release on bail has not been granted
- children under a court ordered secure remand and held in council accommodation;
- children who are subject to a secure accommodation order where the local authority is funding the cost of the secure placement
- children accommodated under the Children Act 1989
- children in a placement that is either directly provided by the local authority or by an approved agency on behalf of the local authority;
- unaccompanied asylum seeking children
- children accommodated in health authority, NHS trust or education placements which are designed to meet the child's social as well as their educational or health needs (eg there are child protection concerns or parenting issues)

Outcomes for children looked after by local authorities in England contains information (derived from matching with the National pupil database) on whether the looked after child has SEN associated with learning disabilities (moderate learning difficulties [MLD], severe learning difficulties [SLD], profound multiple learning difficulties [PMLD]).

In 2014, just over one in four of looked after children have SEN associated with learning disabilities (Figure 6.1; Table 6.2). Using the number of children on school rolls in January 2014 as the denominator (the potential number of children for whom data matching could take place) indicates that the risk per 1,000 children of being looked after continuously for at least 12 months by the local authority as of March 31 2014 was five for all children, 23 for children with MLD, 31 for children with SLD, and 40 for children with PMLD.

Of the looked after children with SEN associated with learning disabilities, the vast majority of children with SLD (87%) and PMLD (90%) were attending special schools. In contrast, the majority of children with MLD (76%) were attending mainstream schools.

Figure 6.1: The percentage of looked after children in 2014 who had SEN associated with learning disability



Adult social care

Statistics related to social care support for people with learning disabilities are largely publicly available through NHS Digital (formerly the Health and Social Care Information Centre) via reports and data tables on the NHS Digital website (<https://digital.nhs.uk/>). Data in this section, with the exception of surveys, are collected by councils with social services responsibilities.

Some aspects of the data collection system for social care have changed over time, with particularly wide-ranging changes introduced in 2014/15. As such, statistics over the time period 2013/14 to 2014/15 cannot be treated as continuous. There were changes to the categories of activity counted, the approach to designating individuals' main reasons for receiving support, and a different approach to estimating the total number of people in the group for whom services could be relevant. To minimise the comparability difficulties we have thus presented numbers of people receiving types of support as opposed to the more usual rates per thousand population.

This chapter provides summaries of the available information (more detailed data tables are available in the accompanying data tables report), organised as follows:

- the number of adults with learning disabilities using residential social care services
- the number of adults with learning disabilities using community social care services (including personal budgets)
- social care assessment and review processes for adults with learning disabilities
- local authority expenditure on social care services for adults with learning disabilities
- the experience of social care reported by adults with learning disabilities

The number of adults with learning disabilities using residential social care services

There is a large amount of data available related to residential services for adults with learning disabilities in England. In 2014/15 there were wide-ranging changes to the statistics collected for social care, meaning that statistics over the time period 2013/14 to 2014/15 cannot be treated as continuous.

Figure 7.1 below presents data on the number of adults with learning disabilities aged 18 to 64 years in England in all forms of accommodation (including non-residential service settings) between 1 April and 31 March 2009/10 to 2014/15 (2009/10 to 2013/14 ASC-CAR Table L2¹; 2014/15 SALT Table LTS004b²). From 2009/10 to 2013/14, these data related to adults with learning disabilities known to local authorities. For 2014/15 these data relate to adults with a primary support reason of learning disability receiving

long-term support from the council, resulting in discontinuities in the data from 2013/14 to 2014/15 (indicated in Figure 7.1 by a vertical line and different shading for 2014/15). Figure 7.1 combines some types of accommodation into larger categories¹, with full details of all types of accommodation available in Table 7.1.

First, the number of working age adults with learning disabilities known to councils slowly increased from 2009/10 to 2013/14 (up to 141,980 adults in 2013/14), as recorded in the line at the top of the figure. In 2014/15 there were reported to be 124,000 working age adults with learning disabilities receiving long-term support from councils. Possible reasons for this difference between 2013/14 and 2014/15 include:

- some adults formerly classified as having a learning disability in social care statistics may have been re-classified as having a primary reason for support of something other than learning disability in 2014/15 (in 2014/15 only a person's primary reason for support is used in the social care statistics). The impact of this change is unknown, although from 2013/14 to 2014/15 the numbers of adults in all support categories were recorded as fewer in 2014/15 than in 2012/13.
- some adults with learning disabilities formerly 'known to councils' may not have been receiving long-term support from their council (for example, receiving short-term support or no support within a particular year), and therefore may not have been counted in the 2014/15 statistics
- some adults with learning disabilities identified by councils up to 2013/14 may have been deemed to be ineligible for support and therefore removed from social care statistics in 2014/15
- services may have been withdrawn for some adults with learning disabilities from 2013/14 to 2014/15

As Figure 7.1 shows, the number of working age adults with learning disabilities in virtually all types of accommodation was smaller in 2014/15 compared to 2013/14. Unknown accommodation was also recorded for the first time in 2014/15.

The most common living situation for working age adults with learning disabilities receiving long-term support from the council was settled living with family/friends (44,785 people in 2014/15, 14.0% fewer than recorded in 2013/14). This difference might be attributed to people living with families being more likely not to be receiving long-term support (and therefore 'dropped' from the statistics in 2013/14 to 2014/15).

¹ Figure 7.1. Tenancy (all types) combines: Tenant (LA/arms length management/registered social landlord/housing association); Tenant (private landlord). Other accommodation (mainly temporary) combines: Staying with family/friends in short term; Mobile accommodation for Gypsy/Roma and Traveller communities; Premises for offenders released from prison or under probation; Rough sleeper/squatting; Night shelter/emergency hostel/direct access hostel; Refuge; Placed in temporary accommodation by LA; Prison/young offenders institution/detention centre/Other temporary accommodation

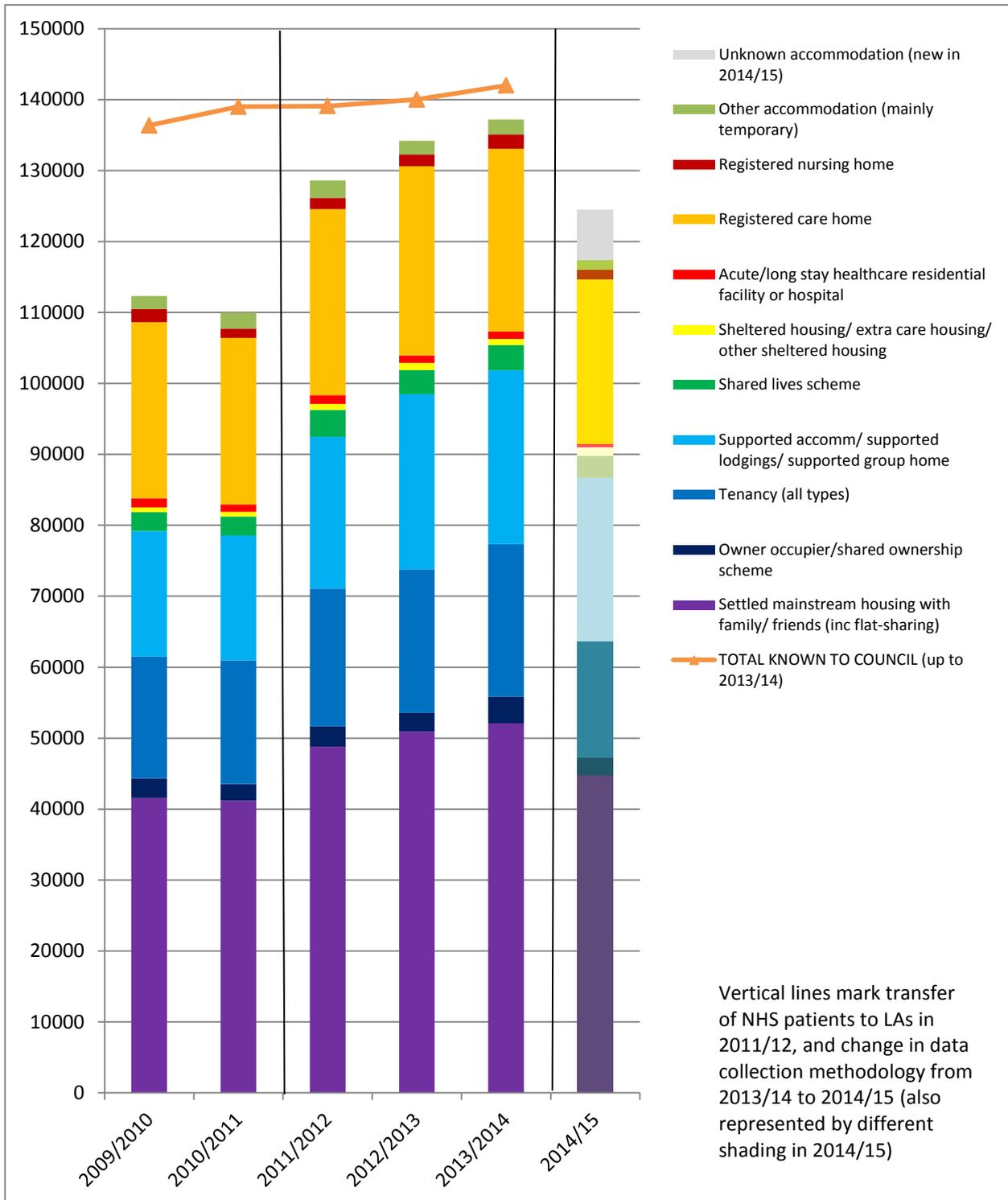
However, similar differences are reported for types of accommodation that can be assumed to be included in the long-term support category.

For example, in 2014/15 23,215 working age adults with learning disabilities were living in registered care homes, (9.9% fewer than recorded in 2013/14 statistics). Also common was some form of supported living, with 23,075 working age adults with learning disabilities in supported accommodation (eg supported living) in 2014/15a (5.8% fewer than in 2013/14. Similarly, 12,425 working age adults with learning disabilities were living in tenancies with local authorities, housing associations or registered social landlords (25.6% fewer than recorded in 2013/14).

Only one form of accommodation was recorded as having higher numbers of working age adults with learning disabilities in 2014/15 than 2013/14. This was sheltered or extra care housing, with 1,195 adults reported (34.3% greater than recorded in 2013/14).

A different data source (RAP Table P2F; see Table 7.2¹) reports 4,800 adults with learning disabilities using short-term residential services supported by local authorities up to 2013/14, although data are not available for 2014/15.

Figure 7.1: Number of adults with learning disabilities in England in accommodation 1 April - 31 March: 2009/10 to 2014/15



The information in Figure 7.1 is also available for individual local authorities and could be converted from numbers to a rate of people with learning disabilities per 100,000 population³ to enable local authorities of different-sized populations to be compared to each other.

Figure 7.2 represents variations across local authorities for the four most common types of accommodation reported in Figure 7.1 for 2013/14: registered care homes, local authority/other tenancies, supported accommodation/group homes and settled arrangements living with family/friends.

The rates of adults with learning disabilities per 100,000 local population in each type of accommodation for each local authority were sorted from lowest to highest. For each box in the graph, the top and bottom of the box show the range for the middle half of local authorities. This is often called the inter-quartile range: rates for a quarter of local authorities are above the top of the box and rates for a quarter of local authorities are below the bottom of the box (the lines coming out of the boxes show the maximum and minimum rates reported by a local authority). The middle line in the box shows the rate for the local authority ranked in the middle (called the median): half of the local authorities will have reported higher rates and half will have reported lower rates. All boxplots for the remainder of this report follow the same format.

Figure 7.2 shows that in the middle-ranked local authority in England in 2013/14, 75 adults with learning disabilities per 100,000 population were living in a registered care home, although this varied greatly between local authorities – adults with learning disabilities at the top quartile of councils were twice as likely as adults at the bottom quartile to be living a residential care home (100 vs 50 adults per 100,000 population). Figure 7.2 shows similar variation across local authorities for other forms of accommodation.

It is important to note the extreme variation of outliers. For example, the ten councils reporting the highest rates of people with learning disabilities in care homes reported rates from 120 to 180 people per 100,000, whilst the ten lowest reporting councils reported fewer than 15 people per 100,000). A range of council types were represented in both high and low reporting councils. Similar variations at the extremes are also found for the other indicators in Figure 7.2.

Figure 7.2: Variations across local authorities in the number of adults with learning disabilities per 100,000 population in residential services in 2013/14

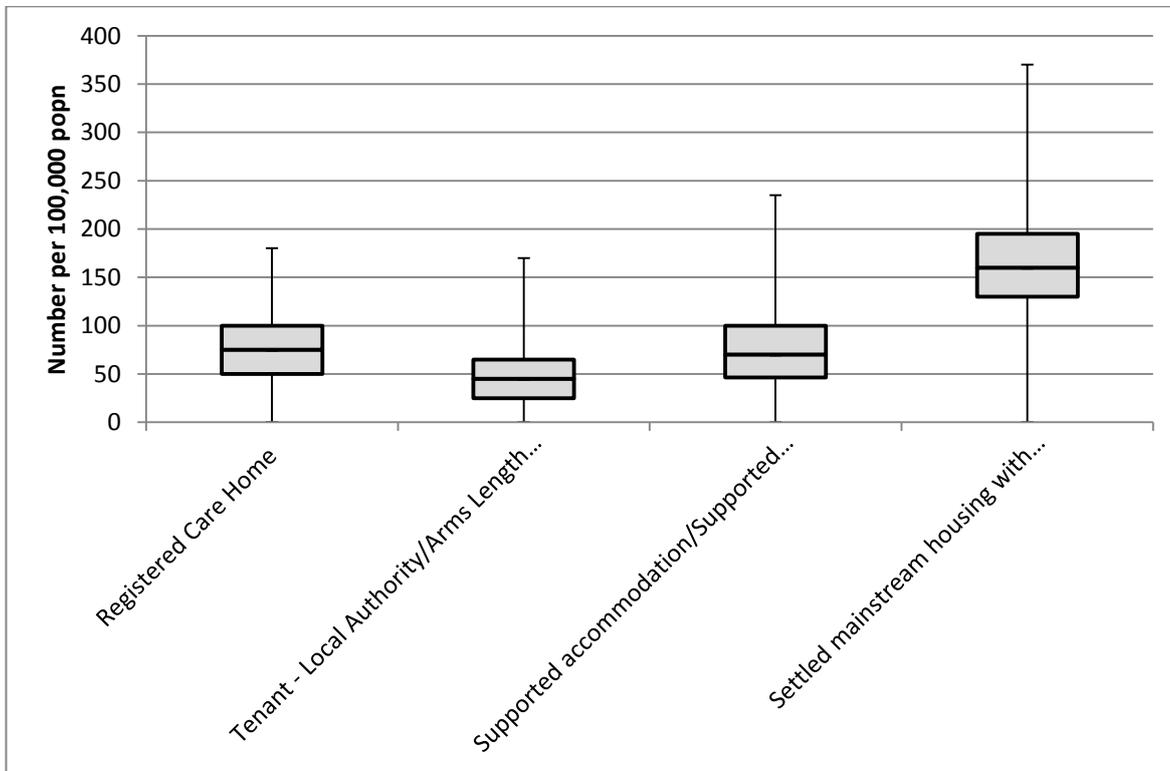


Figure 7.3 below presents data on the number of all adults with learning disabilities aged 18+ in England receiving council-funded residential support in the form of nursing care or residential care, reported annually from 2005/06 to 2014/15 (see Table 7.3, including breakdown by age band; ASC-CAR Table S1¹ and for 2014/15 in SALT Table LTS001a²). Major changes in social care data collection and reporting for 2014/15 means that statistics up to 2013/14 and for 2014/15 cannot be assumed to be continuous (indicated in Figure 7.3 by a vertical line and different shading for 2014/15). When interpreting Figure 7.3, it is also important to note that an estimated 1,840 adults with learning disabilities in residential care in 2011/12 were already in residential care under NHS funding, but transferred to local authority responsibility (with funding also transferring) under Valuing People Now for 2011/12⁴. Therefore Figure 7.3 adds in this figure for years before 2011/12.

According to these data sources, across all adult age groups 30,500 adults with learning disabilities aged 18+ were living in residential care at the end of 2014/15. Data on specific sectors of residential care service provider are available up to 2013/14. These data report that 95% of adults with learning disabilities in residential care were living in independent sector rather than local authority staffed residential care.

Smaller numbers of adults with learning disabilities (1,730 people) were living in nursing care in 2014/15.

Overall there has been a steady decline in the numbers of adults with learning disabilities living in both residential care and nursing care. Steady decreases in the larger number of adults with learning disabilities aged 18 to 64 years in both residential and nursing care, are partially offset by steady increases in the smaller number of adults aged 65 years or over living in residential and nursing care.

Figure 7.3: Number of adults with learning disabilities in England supported by local authorities at 31 March in residential care: 2005/06 to 2014/15

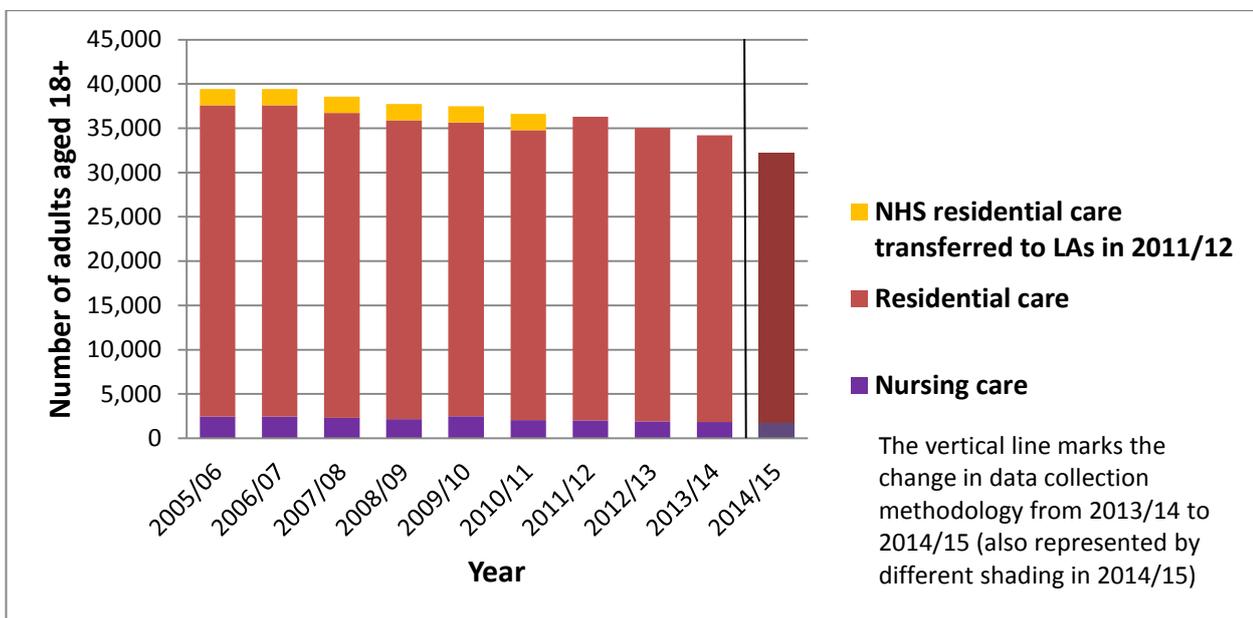
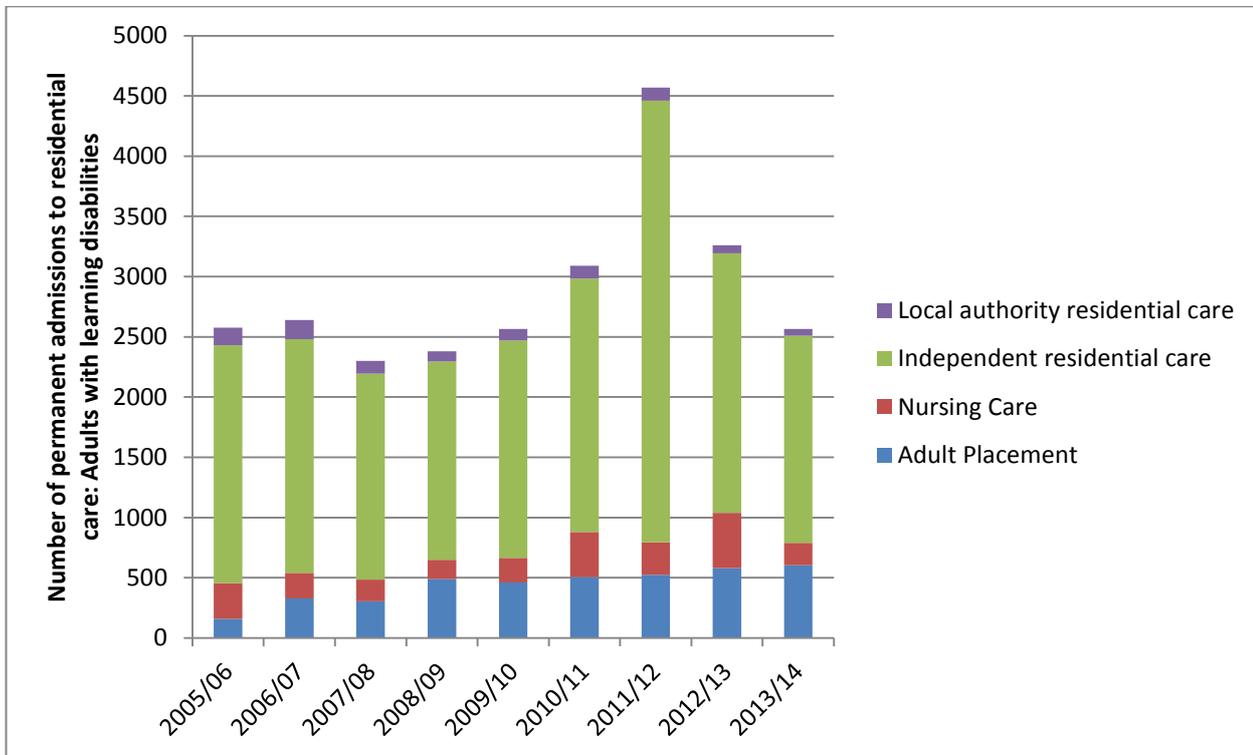


Figure 7.4 below presents data on the number of adults with learning disabilities in England permanently admitted to the types of residential care reported in Figure 7.3, reported annually from 2005/06 to 2013/14 (see Table 7.4 including breakdown by age band). These data are not available for 2014/15. When interpreting Figure 7.4, it is important to note that an estimated 1,840 adults with learning disabilities were already in residential care under NHS funding, but under Valuing People Now transfers from NHS to local authority responsibility counted as permanent admissions to local authority residential care in 2011/12⁴.

As Figure 7.4 shows, increased numbers of permanent admissions to residential care in the years 2010/11 to 2012/13 seem to have reduced in 2013/14.

Figure 7.4: Number of adults with learning disabilities in England permanently admitted to residential care: 2005/06 to 2013/14



The number of adults with learning disabilities using community social care services (including personal budgets)

Up to 2013/14, there was a substantial amount of data available concerning community (ie non-residential) social services for adults with learning disabilities in England. In 2014/15, this was replaced by statistics recording, amongst the 140,000 adults with learning disabilities receiving long-term social care support, whether they were using:

- residential care (reported above),
- various forms of personal budget (reported below) or
- council-commissioned support only (this category can include any form of support except residential or nursing care, so includes supported living and tenancies): the council-commissioning support only figure was 13,430 adults aged 18+ years (SALT Table LTS001a).

The 2014/15 statistics do not record the numbers of people using the types of community-based social services reported up to 2013/14.

Figure 7.5 below presents data concerning the numbers of adults with learning disabilities aged 18+ using a range of non-residential community services supported by

local authorities, from 2005/06 to 2013/14 (see Table 7.5 for a more detailed table, broken down by age bands; RAP Table P2F¹).

As Figure 7.5 shows, overall 117,025 adults with learning disabilities were using some form of community service in 2013/14, with the number steadily increasing from 2005/06 (compound increase 1.6% per year).

In terms of specific community services, the service used by the largest number of adults with learning disabilities was still day services (used by 49,555 people in 2013/14), although this number has steadily declined year on year from 58,020 people in 2005/06 (compound decrease 2.0% per year).

Home care services in 2013/14 were used by 43,025 adults with learning disabilities, with numbers increasing year on year from 26,670 people in 2005/06 (compound increase 6.2% per year).

Professional support in 2013/14 was used by 21,035 adults with learning disabilities. Professional support is defined as a service included as part of the person's care plan, where a professional provides active, on-going support which may take the form of therapy, support or professional input (eg from social workers, occupational therapists or counsellors). It does not include care management. From 2005/06 (38,155 people) to 2008/09 (43,810 people) there was a steady increase in the number of people accessing professional support (compound increase 4.7% per year). From 2008/09 to 2013/14 there has been a sharp decrease (compound decrease -13.7% per year).

The use of equipment and adaptations (including telecare) has rapidly increased from 5,980 adults with learning disabilities in 2005/06 to 11,095 people in 2013/14 (compound increase 8.0% per year). To be recorded in these statistics, an item of equipment has to be part of a person's care plan (rather than a basic service such as a walking stick or bath rail) and has to require an ongoing financial commitment from the local authority (eg in rental or regular maintenance).

'Other services' for adults with learning disabilities have also steadily increased over time, from 17,020 people in 2005/06 to 23,430 people in 2013/14 (compound increase 4.1% per year). For a service to be reported as 'other' it has to be part of a person's care plan and not reportable in any of the other categories.

Figure 7.5: Number of adults with learning disabilities aged 18+ using a range of non-residential community services supported by local authorities: 2005/06 to 2013/14

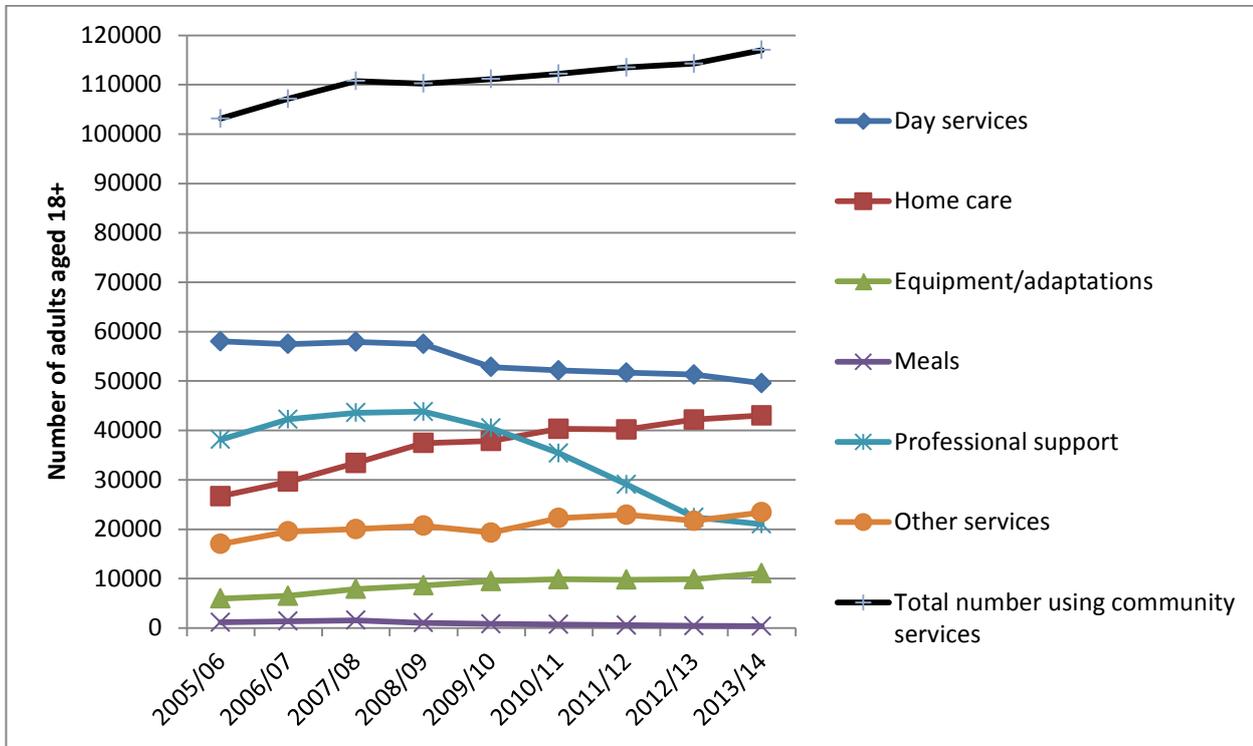


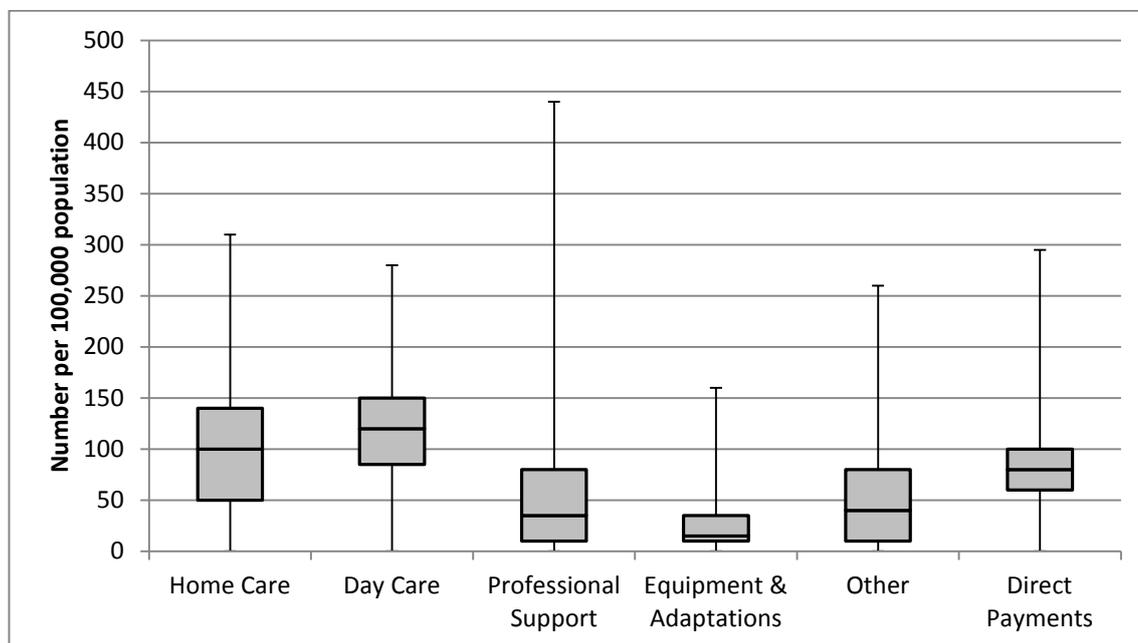
Figure 7.6 represents variations across local authorities for the most common community services reported in Figure 7.5, with the addition of direct payments.

Figure 7.6 shows that in the middle-ranked local authority in England in 2013/14, 115 adults with learning disabilities per 100,000 population were using a day service, although this varied greatly between local authorities – adults with learning disabilities at the top quartile of councils were 1.7 times as likely as adults at the bottom quartile to be using a day service (145 vs 85 adults per 100,000 population).

Bigger variations are found for home care, with a median 100 adults with learning disabilities per 100,000 population using home care but people at the top quartile were 2.8 times as likely to use home care than people at the bottom quartile (140 vs 50 adults per 100,000 population). Even bigger variations are found for professional support, equipment/adaptations and other support, with less variation for direct payments.

It is important to note the extreme variation of outliers. For example, the ten councils reporting the highest rates of people with learning disabilities receiving home care reported rates of 200 people per 100,000 and above, whilst the ten lowest reporting councils reported rates of 15 people per 100,000 or fewer. A range of council types were represented in both high and low reporting councils. Similar variations at the extremes are also found for the other indicators in Figure 7.6.

Figure 7.6: Variations across local authorities in the number of adults with learning disabilities per 100,000 population using a range of community services in 2013/14



Statistics on the number of adults with learning disabilities using direct payments and self-directed support have been collected since 2009/10. Self-directed support can be provided either through direct payments or through other delivery mechanisms (such as brokered personal budgets, individual service funds or personal budgets administered by local authorities). Figure 7.7 below presents this data for adults aged 18 to 64 years for 2009/10 through to 2014/15 (see Table 7.6 for a more detailed data table; RAP Table SD1¹; SALT Table LTS001a²). Major changes in social care data collection and reporting for 2014/15 means that statistics up to 2013/14 and for 2014/15 cannot be assumed to be continuous (indicated in Figure 7.7 by a vertical line and different shading for 2014/15).

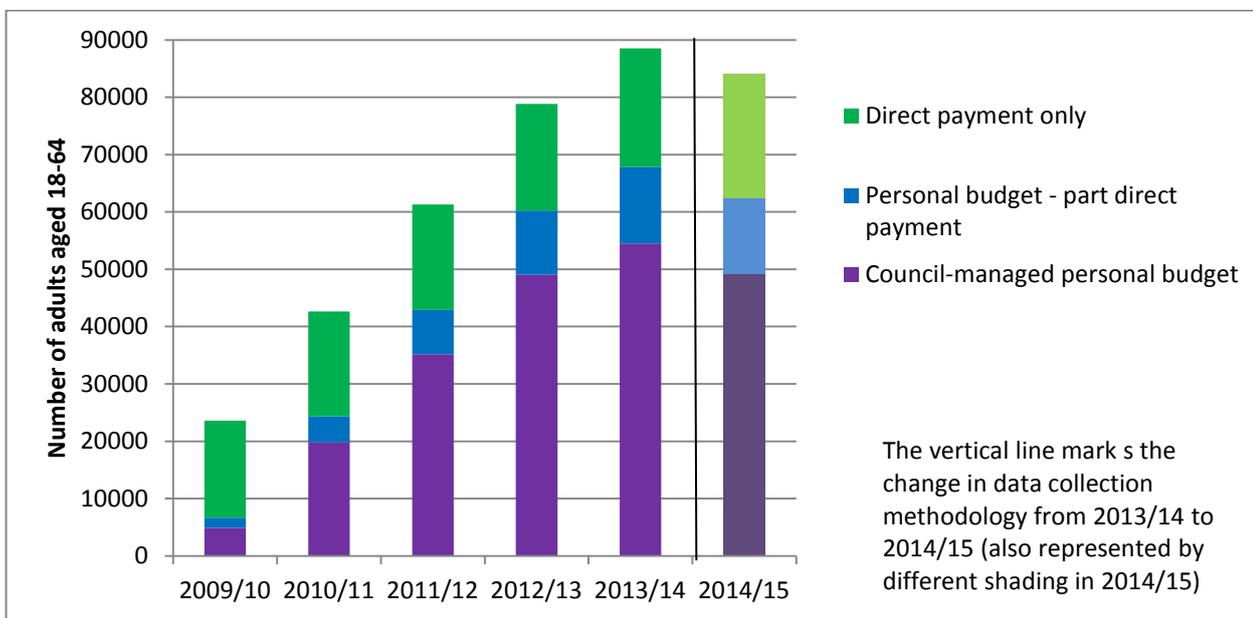
Figure 7.7 shows that 83,995 adults with learning disabilities aged 18 to 64 years in 2014/15 were reported by local authorities to be making use of self-directed support, with 21,580 adults using a direct payment, 13,265 adults using self-directed support partly involving a personal budget and 49,150 adults using self-directed support in the form of a council-managed personal budget.

These figures show substantial increases from 2009/10 to 2013/14. The smaller numbers of working age adults with learning disabilities recorded as using self directed support in 2014/15 may be a function of changes to social care statistics in 2014/15. For example, the change in reporting to only those people receiving long-term support in 2014/15 may have resulted in people formerly included in these statistics being excluded (for example, people receiving one-off personal budget payments). Most of the

big increase in self-directed support from 2009/10 to 2013/14 is accounted for by increases in the number of people receiving council-managed personal budgets, with the number of people using direct payments increasing more slowly. There have been some questions^{5,6} about the extent to which these forms of self-directed support represent a change from ‘traditional’ models of council service usage.

The figures for 2014/15 for the first time include figures for adults with learning disabilities aged 65 years or over using personal budgets. In this age group, 620 people were using direct payments only, 505 were using personal budgets partly involving direct payments, and 5,920 were receiving council-managed personal budgets.

Figure 7.7: Number of adults aged 18 to 64 years with learning disabilities getting a direct payment (DP)/self-directed support (SDS): 2009/10 to 2014/15

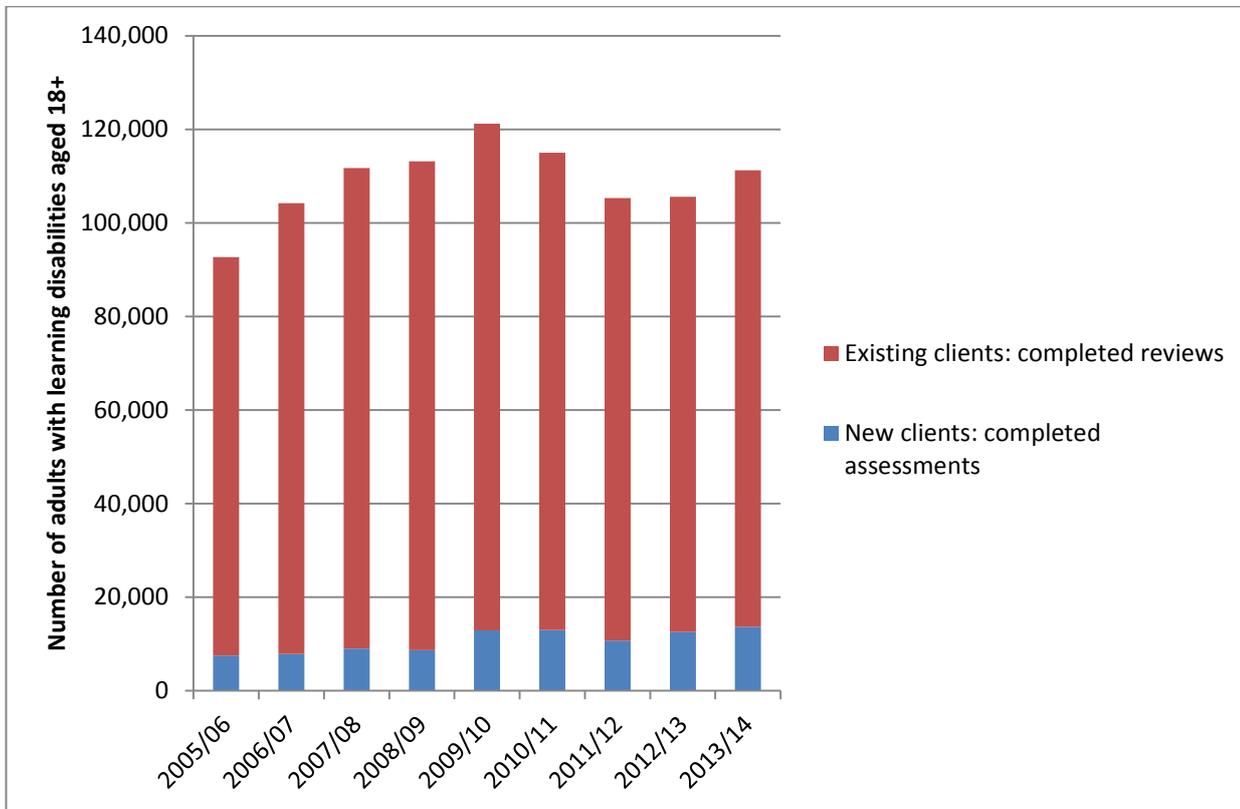


Social care assessment and review processes for adults with learning disabilities

There is some data available concerning social care assessment and processes for adults with learning disabilities in England, although with some changes in the data collected over time (see previous reports) and a major change in 2014/15.

Figure 7.8 below (see Table 7.7 for a more detailed data table, broken down by age band) presents data from Tables A1, A7 and A11B from the NASCIS RAP dataset¹. In combination, these tables provide data from 2005/06 to 2013/14 on the number of adults with learning disabilities new to social services who have received a completed assessment (13,665 people in 2013/14), and the number of existing adults with learning disabilities using social care who have received a review (97,550 people in 2013/14).

Figure 7.8: Number of new and existing adults with learning disabilities aged 18+ with a completed assessment or review 1 April to 31 March: 2005/06 to 2013/14



As Figure 7.8 shows, the numbers of reported first assessments and reviews have both fluctuated over time from 2005/06 to 2013/14, although overall there has been a more rapid increase in the number of first assessments (CAGR increase +7.7% per year) compared to the number of reviews (CAGR increase +1.7% per year). It is worth noting that the total number of adults with assessments and reviews in 2013/14 (111,215 people) was fewer than the number of adults with learning disabilities known to local authorities (141,980 people) although not everyone with learning disabilities known to the council will meet eligibility criteria for social care support.

In 2014/15, statistics were collected on ‘requests for support’ from new and existing users of social care support, although the only data disaggregated for people with learning disabilities is where the sequel to a request for support is ‘short-term support to maximise independence’. These data for adults with learning disabilities in 2014/15 are available in Table 7.8².

Local authority expenditure on social care services for adults with learning disabilities

Publicly available statistics on local authority expenditure have changed substantially in 2014/15. Up to 2013/14, statistics were only available on gross social services expenditure on services for adults with learning disabilities aged 18 to 64 years old, using the categories presented in Figure 7.9 below (PSS-EX1; see Table 7.9 for a detailed data table⁷). From 2014/15 data are also available for adults with learning disabilities aged 65 years or over, although the categories of reported spending have changed considerably (ASC-FR; see Table 7.9 for a detailed data table⁸). Throughout this section, inflation-adjusted figures have been calculated by using the Personal Social Services Research Unit annual percentage increases for adult services (all sectors) pay and prices index (excluding capital)⁹.

When interpreting all expenditure tables, it is crucial to note that gross expenditure costs for 2011/12 include costs transferred from the NHS to social services under Valuing People Now (for people with learning disabilities). An estimated total of £872 million was transferred from the NHS to local authorities under Valuing People Now and NHS transfer schemes¹⁰. However, these transfer figures cannot be broken down into specific categories of expenditure.

Therefore, the recorded increase in gross expenditure for all services for adults with learning disabilities aged 18 to 64 from 2010/11 to 2011/12 of £880 million is fully accounted for by transfers from the NHS to local authorities and does not represent real increases in state funding for services for adults with learning disabilities.

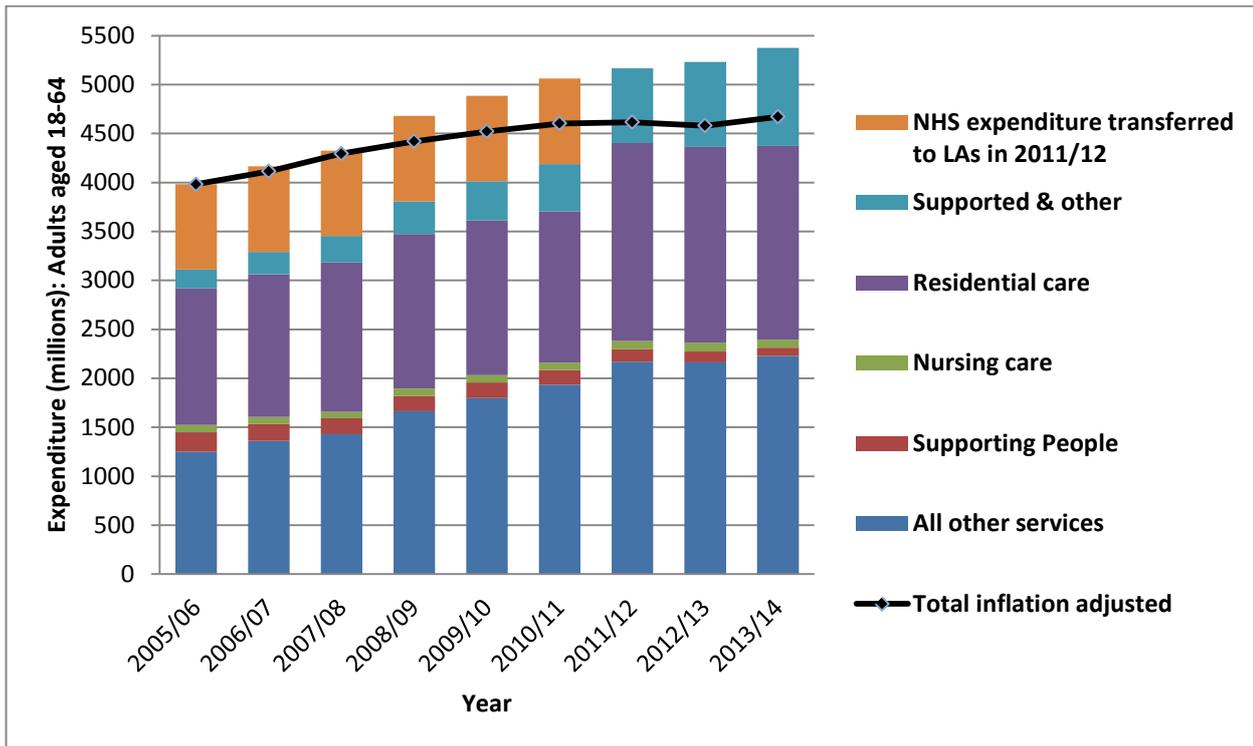
Taking first the expenditure figures up to 2013/14, Figure 7.9 shows that in 2013/14, the total gross expenditure recorded by local authorities for social care for working age adults with learning disabilities was £5.38 billion. Alongside this figure, it should be noted that local authorities also reported receiving relevant income totalling £722 million (£296 million from the NHS, £264 million from client contributions, £82 million from joint arrangements and £81 million from 'other').

By far the largest component of local authority expenditure relating to residential services for adults with learning disabilities aged under 65 was on residential placements (£1.98 billion). This was followed by supported and other accommodation (£1 billion) then, some way behind, nursing care placements (£82 million). Supporting People expenditure in 2013/14 was £85 million.

Overall, social services spending from 2005/06 to 2013/14 more than kept pace with inflation (see the black line in Figure 7.9). From 2011/12 to 2013/14 absolute reductions in spending on residential care, nursing care and Supporting People (a collective

reduction of £85.6 million) was more than offset by an increase in spending on supported and other accommodation (an increase of £236.6 million). It is unclear how much of these changes in spending are the result of actual changes in accommodation rather than the recategorisation/remodelling of existing residential care services as supported accommodation.

Figure 7.9: Local authority gross current expenditure on social services for adults with learning disabilities aged 18 to 64 years (in millions): 2005/06 to 2013/14



Gross social services expenditure on community services for adults with learning disabilities aged 18 to 64 years old up to 2013/14 is presented in Figure 7.10 below (PSS-EX1; see Table 7.10).

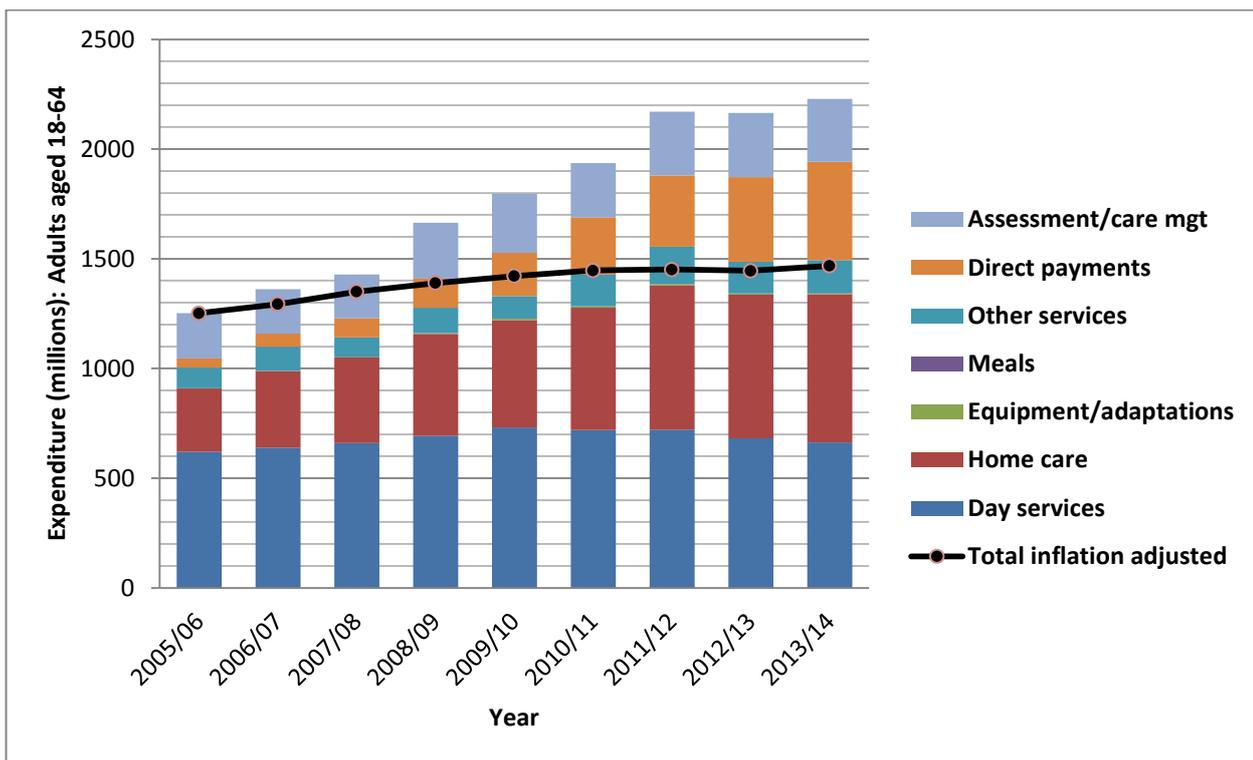
As mentioned above, it is crucial to note that gross expenditure costs for 2011/12 include a total of £872 million in costs transferred from the NHS to social services under Valuing People Now and other schemes⁹. However, these transfer figures cannot be broken down into specific categories of expenditure so they cannot be factored into Figure 7.10 concerning community services.

Figure 7.10 shows that in 2013/14, for the first time local authority spending on home care for working age adults with learning disabilities (£676 million) was greater than spending on day services (£663 million), with considerable expenditure on direct payments (£449 million). Expenditure on other community services was smaller (other community services £149 million; equipment/adaptations £5.5 million; meals £0.5 million).

From 2005/06 to 2010/11, local authority spending on community services for working age adults with learning disabilities outpaced inflation, with some signs of a plateau in spending after 2010/11 (see the black line on Figure 7.10). Although there are fluctuations, spending on day services reduced while spending on home care and direct payments increased. Information is not collected on what forms of support are purchased via direct payments.

In 2013/14, local authorities were spending £286 million on assessment and care management for adults with learning disabilities aged 18 to 64 . Taking inflation into account, from 2005/06 to 2013/14 there was a steady increase in local authority expenditure on assessment and care management for adults with learning disabilities aged under 65 (CAGR increase at constant prices +2.4% per year), although there are signs of spending remaining broadly static for 2011/12 to 2013/14.

Figure 7.10: Local authority gross current expenditure on community services for adults with learning disabilities aged 18 to 64 years: 2005/06 to 2013/14



In a similar format to Figure 7.2, Figure 7.11 presents data on variations in social services expenditure across local authorities in 2013/14.

Figure 7.11 shows that the middle ranked local authority in England spent £4.3 million per 100,000 population on residential care placements for adults with learning disabilities aged 18 to 64 years, although this varied greatly between local authorities – the ten councils reporting the highest amounts spent £7.53 million or more per 100,000

population, whilst the ten councils reporting the lowest amounts spent £1.79 million or less per 100,000 population.

There was even greater variation in spending on supported accommodation for working age adults with learning disabilities, with a median spend of £2.1 million per 100,000 population, with the ten highest spending local authorities spending £6.15 million or more per 100,000 population on supported accommodation and the ten lowest spending local authorities spending nothing on supported accommodation.

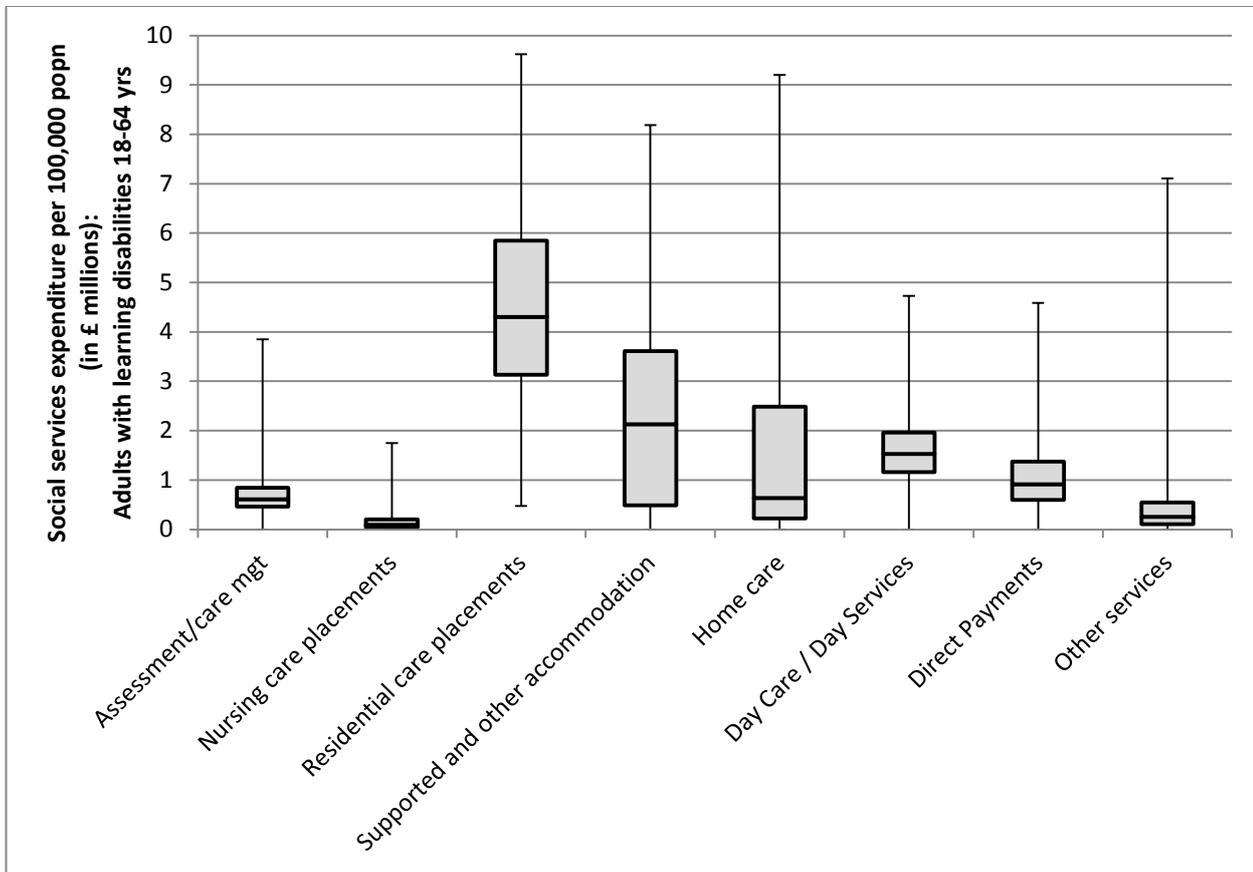
Figure 7.11 also shows large variation in spending on home care for working age adults with learning disabilities, with a median spend of £0.6 million per 100,000 population, compared to the ten highest spending local authorities (£4.8 million or more per 100,000 population) and the ten lowest spending local authorities (£65,000 or less per 100,000 population).

Variation in spending on day services, while still substantial, was not as large (median £1.5 million per 100,000 vs £2.5 million or more per 100,000 for the ten highest spending councils and £650,000 or less per 100,000 for the ten lowest spending councils).

Variations in spending on direct payments across local authorities (median £0.9 million per 100,000 vs £2.4 million or more per 100,000 for the ten highest spending councils and £360,000 or less per 100,000 for the ten lowest spending councils) and assessment/care management (median £0.6 million per 100,000 vs £1.4 million or more per 100,000 for the ten highest spending councils and £295,000 or less per 100,000 for the ten lowest spending councils) were less extreme, although still substantial.

All these variations in spending included a range of types of council at both the high spending and low spending extremes.

Figure 7.11: Variations across local authorities in social services gross current expenditure (in £ millions) per 100,000 population on social care for adults with learning disabilities aged 18 to 64 years in 2013/14



Local authority gross current expenditure on support for adults with learning disabilities, using the categories reported in 2014/15, is available for adults aged 18 to 64 years and, for the first, time, for adults aged 65 years or over.

For adults with learning disabilities aged 18 to 64 years, the total gross social services expenditure on social care in England was £4.437 billion.

For adults with learning disabilities aged 65 years or over, the total gross social services expenditure on social care in England was £540 million.

Figure 7.12a and 7.12b present details of the proportions of expenditure in specific spending categories for adults with learning disabilities aged 18 to 64 years and adults with learning disabilities aged 65 years or over.

As Figure 7.12 shows, for adults aged 18 to 64 years, the biggest category of long-term support expenditure was residential care (£1.7 billion), followed by supported living (£933 million), other long-term community support (£613.2 million), direct payments

(£454 million), home care (£349 million), supported accommodation (£274 million) and nursing care (£58 million). Compared to the £4.4 billion in total spent on long-term support for working age adults with learning disabilities, only £60 million in total was spent on short-term support.

Figure 7.13 shows that the biggest category of long-term support expenditure for adults with learning disabilities aged 65+ years was also residential care (£251 million), followed by supported living (£111 million), other long-term community support (£47 million), home care (£45 million), supported accommodation (£32 million), nursing care (£27 million) and direct payments (£20 million). Compared to the £534 million spent on long-term support for adults with learning disabilities aged 65+ years, only £6 million in total was spent on short-term support.

Figure 7.12: Local authority gross current expenditure (in £ millions) on supports for adults with learning disabilities aged 18 to 64 years: 2014/15

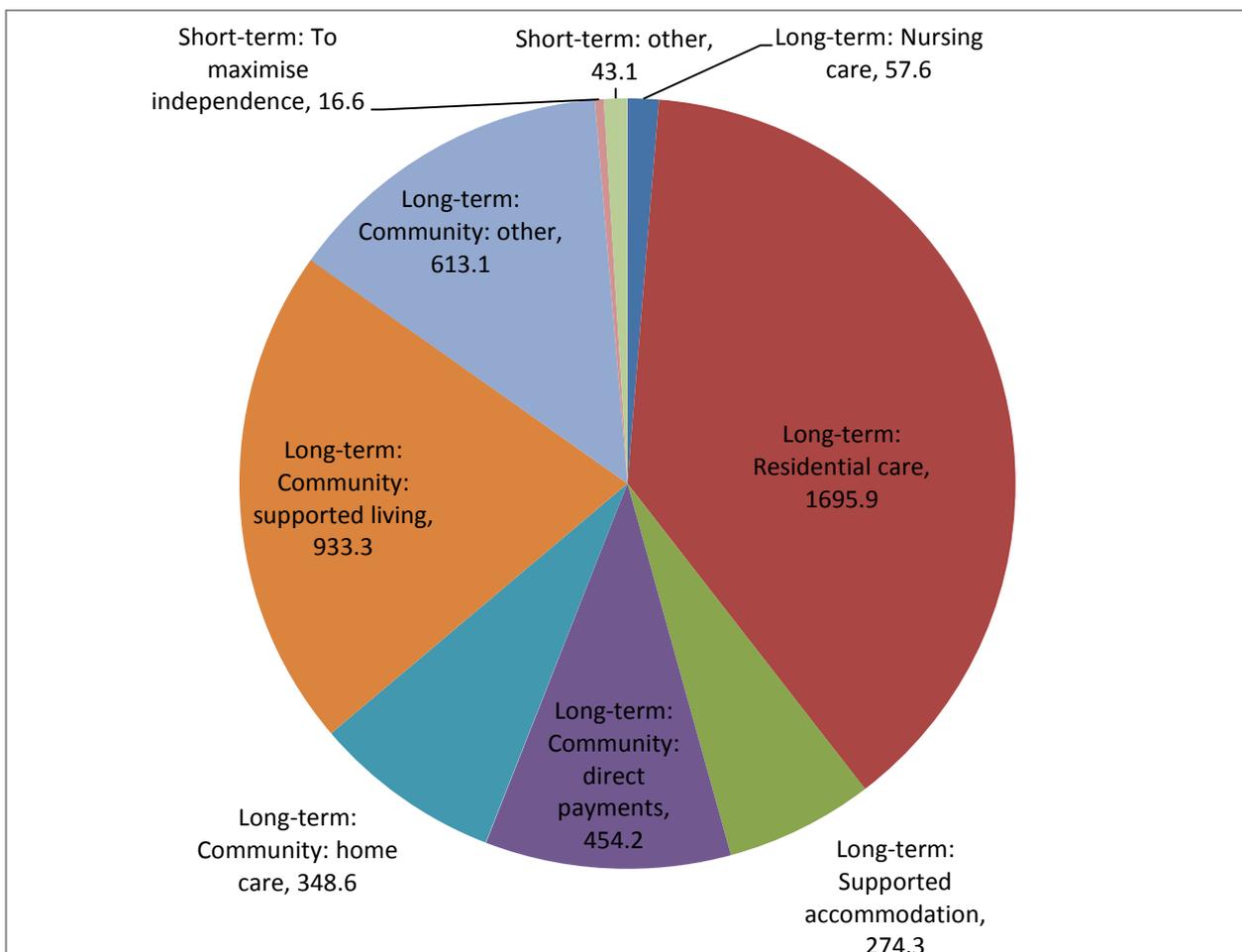
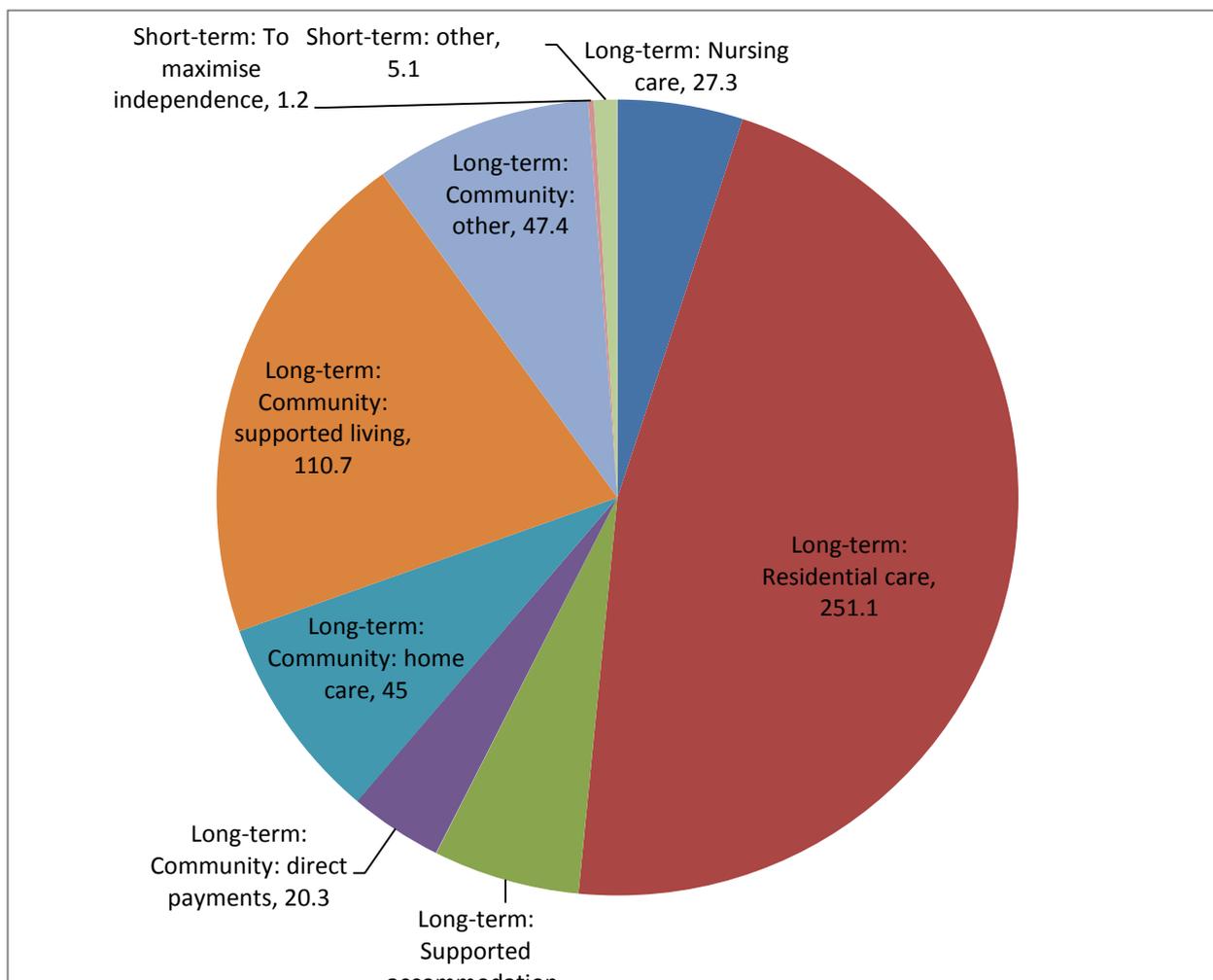


Figure 7.13: Local authority gross current expenditure (in £ millions) on supports for adults with learning disabilities aged 65 years or over: 2014/15



Comparability between 2014/15 and earlier years in expenditure statistics cannot be assumed. First, as mentioned earlier, the re-categorisation of services into short-term and long-term may have resulted in the population of adults with learning disabilities reported by councils as receiving social care reducing from 2013/14 to 2014/15. Second, some of the categories of expenditure reported in earlier years specifically for adults with learning disabilities may now wholly or partly fall within expenditure categories that are not reported specifically for adults with learning disabilities (eg assistive technology and equipment; social care activities; information and early intervention; commissioning and service delivery).

Figure 7.14 below is an attempt to report comparable categories of expenditure from 2005/06 to 2014/15 for adults with learning disabilities aged 18 to 64 years, using the assumptions in Box 7.1 below. Figure 7.14 indicates the discontinuity of expenditure data between 2013/14 and 2014/15 using a vertical line and different shading for 2014/15 data.

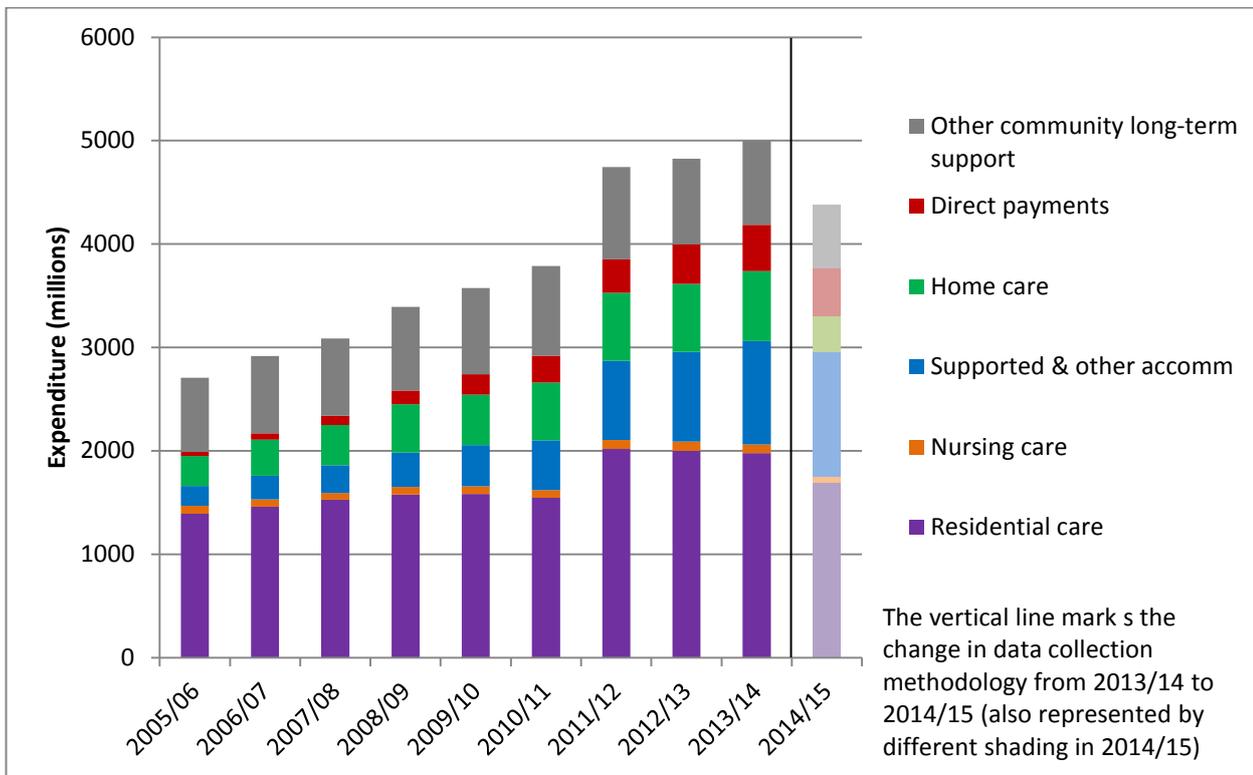
Box 7.1: Categories of expenditure for comparison over time

2005/06 category of expenditure	2014/15 category of expenditure
Residential care	Long-term: residential care
Nursing care	Long-term: nursing care
Supported and other accommodation	Long-term: supported accommodation Long-term: supported living
Home care	Long-term: home care
Direct payments	Long-term: direct payment
Day services Meals Other community services	Long-term: other long-term support

Using these assumptions, Figure 7.13 shows gross current expenditure of local authorities on services for adults with learning disabilities aged 18 to 64 years from 2005/06 to 2014/15. When interpreting these data, it is important to note that these figures are not inflation adjusted. It is also important to remember the transfer of £872 million (with accompanying responsibilities) from the NHS to local authorities in 2011/12 (see earlier), which accounts for the apparent sharp increase in funding for residential care in 2011/12.

Bearing in mind the caveats about comparability of populations and expenditure categories from 2013/14 to 2014/15, Figure 7.13 shows that expenditure on residential care, home care, other long-term community support, and to a lesser extent nursing care, was recorded as lower in 2014/15 than 2013/14. Estimated rates of inflation for adult social care services during this time period are low (pay and prices 0.7% in 2013/14; 0.2% in 2014/15). Recorded expenditure on direct payments was similar in 2013/14 and 2014/15. Expenditure on supported accommodation was recorded as higher in 2014/15 than 2013/14.

Figure 7.14: Local authority gross current expenditure on services for adults with learning disabilities aged 18 to 64 years: 2005/06 to 2014/15



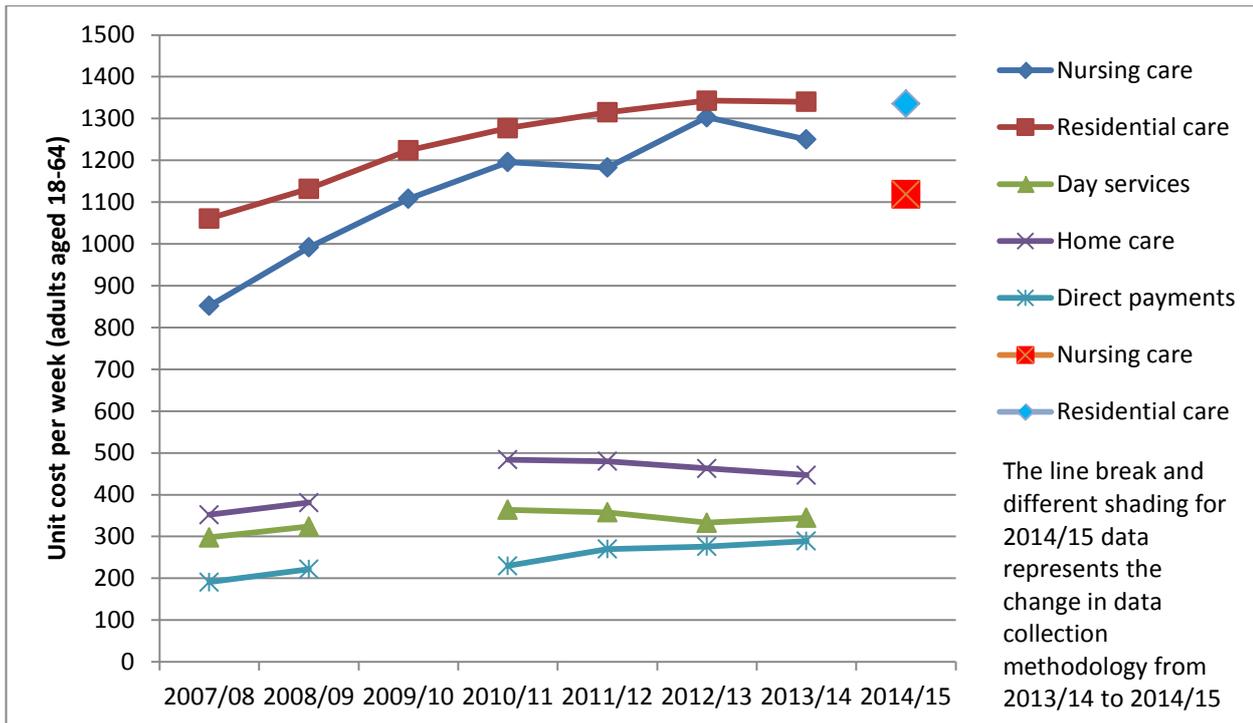
Data are also available from 2007/08 on the unit costs of a range of social care services for adults with learning disabilities aged 18 to 64 , presented in Figure 7.12 below (see Table 7.11 for a more detailed table; PSS-EX1 Unit Costs table; ASC-FR unit costs table⁵). Unit costs data up to 2014/15 are available for residential and nursing care⁶; unit costs data for home care, day services and direct payments are only available up to 2013/14. As it cannot be assumed that unit costs data are continuous from 2013/14 to 2014/15, Figure 7.12 presents an unbroken line up to 2013/14 and different shading for 2014/15 unit costs data.

Regarding residential social services for adults with learning disabilities, Figure 7.12 shows that in 2014/15, the weekly unit cost of nursing care was £1,119 per person aged 18 to 64 years per week, and the weekly unit cost of residential care was £1,336 per person aged 18 to 64 years per week. Taking into account inflation, the unit costs of both nursing care and residential care increased from 2007/08 to 2012/13. Since then, the cost of residential care stabilised whilst the cost of nursing care fell by about 15%. In the absence of actual cuts in pay rates, the only plausible explanations for this fall in the unit cost of nursing care would be reduced time for each client or reductions in staff grades.

For the first time in 2014/15, data are also available on the unit costs of nursing and residential care for adults with learning disabilities aged 65 years or over (see Table 7.11). The unit costs of both nursing care (£741 per person per week) and residential

care (£899 per person per week) for adults with learning disabilities aged 65 years or more were considerably lower than for younger adults with learning disabilities. Figure 7.15 shows that the unit costs of day services, home care and direct payments, while rising from 2007/08 to 2010/11, have been held fairly static or even reduced slightly from 2010/11 to 2013/14 (data are not available for 2014/15).

Figure 7.15: Local authority unit costs per week of social services for adults with learning disabilities aged 18 to 64 years (not inflation adjusted)



The experience of social care reported by adults with learning disabilities

Starting from 2011/2012, NHS Digital have conducted an annual national survey of adult users of personal social services¹¹. This investigates various aspects of adults’ experiences of adult social care. From January to March 2015, a stratified random sample of adults currently using local authority commissioned social care were surveyed. This included a request to local authorities to try to contact all adult social service users with learning disabilities. An easy read version of the survey questionnaire was developed and distributed via local authorities. Most of the respondents with learning disabilities used this easy read version.

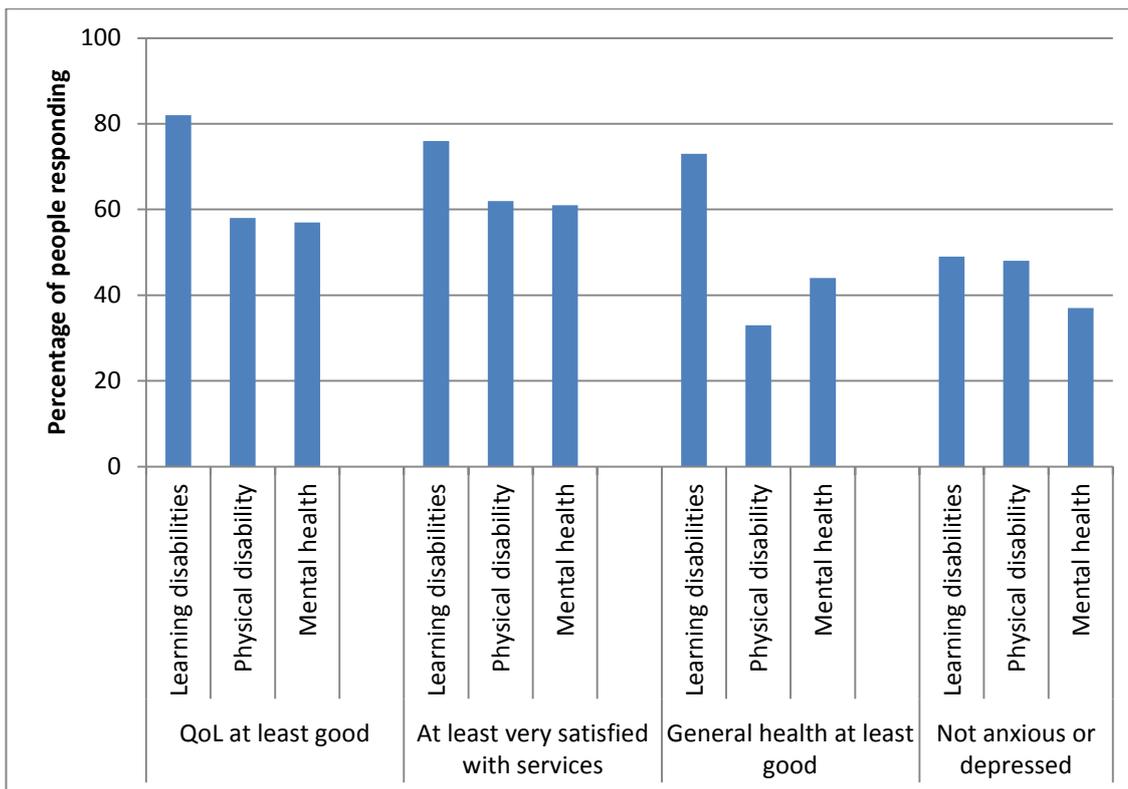
Figure 7.16 below reports selected findings from the survey for 2014/15 for adults with learning disabilities, adults with physical disabilities and adults with mental health difficulties (see Table 7.12 for a detailed data table, including data from 2011/12 to

2013/14). Where data are available for more than one year they show remarkable consistency over time.

As Figure 7.16 shows, people with learning disabilities reported markedly more positive experiences of social care services and of their own health (with the exception of present state anxiety/depression) than other groups (this trend is also noticeable in other indicators not reported here). This was particularly noticeable in the proportion using the extreme positive end of possible response options.

These differences may partially be accounted for by the easy read version of the survey completed by the majority of people with learning disabilities. Another difference is likely to be that people with learning disabilities were less likely than people with physical disability or people with mental health problems to have completed the survey by themselves (7% vs 27% and 37%), and more likely to have had help to complete the survey from a care worker (52% vs 18% and 25%).

Figure 7.16: Adult service user experiences of social care 2014/15



Employment

Councils with adult social services responsibilities provide data to NHS Digital on the numbers of working age adults with learning disabilities in all forms of work, including paid/self employment and voluntary (unpaid) employment, broken down by hours per week of regular employment. The figures concern adults with learning disabilities aged 18 to 64 years known to Councils with adult social services responsibilities (CASSRs) in paid/self employment. As with other statistics collected via local authorities, some aspects of the data collection system for employment have changed over time, with particularly wide-ranging changes introduced in 2014/15 (see the Adult Social Care section). As such, statistics over the time period 2013/14 to 2014/15 cannot be treated as continuous. In addition, for 2014/15, statistics relating to the number of people in voluntary work are no longer collected. Where relevant, this discontinuity in data is shown in graphs by a vertical line and different shading for 2014/15 data.

This chapter provides a summary of the available information (more detailed data tables are available in the data tables report).

Figure 8.1 below shows the number of working age adults (aged 18 to 64 years) with learning disabilities known to councils engaged in any paid/self employment or engaged only in voluntary work (see Table 8.1 for more details; ASCOF 1E; ASC-CAR L1¹; SALT LTS004a²). Setting aside the first year of incomplete data collection (2008/09), the number of adults in any paid/self employment rose slightly to a peak of 9,905 people in 2011/12, dropping gradually to 9,580 people in 2013/14. Under a different data collection regime, the number of adults with learning disabilities in any paid/self employment was recorded as 7,430 people in 2014/15. The number of adults engaged in voluntary work only generally increased over time to 9,240 people in 2013/14, the last year for which data were collected.

Figure 8.1: Number of working age (18 to 64 years) adults with learning disabilities known to councils engaged in any paid/self employment or engaged in voluntary work only

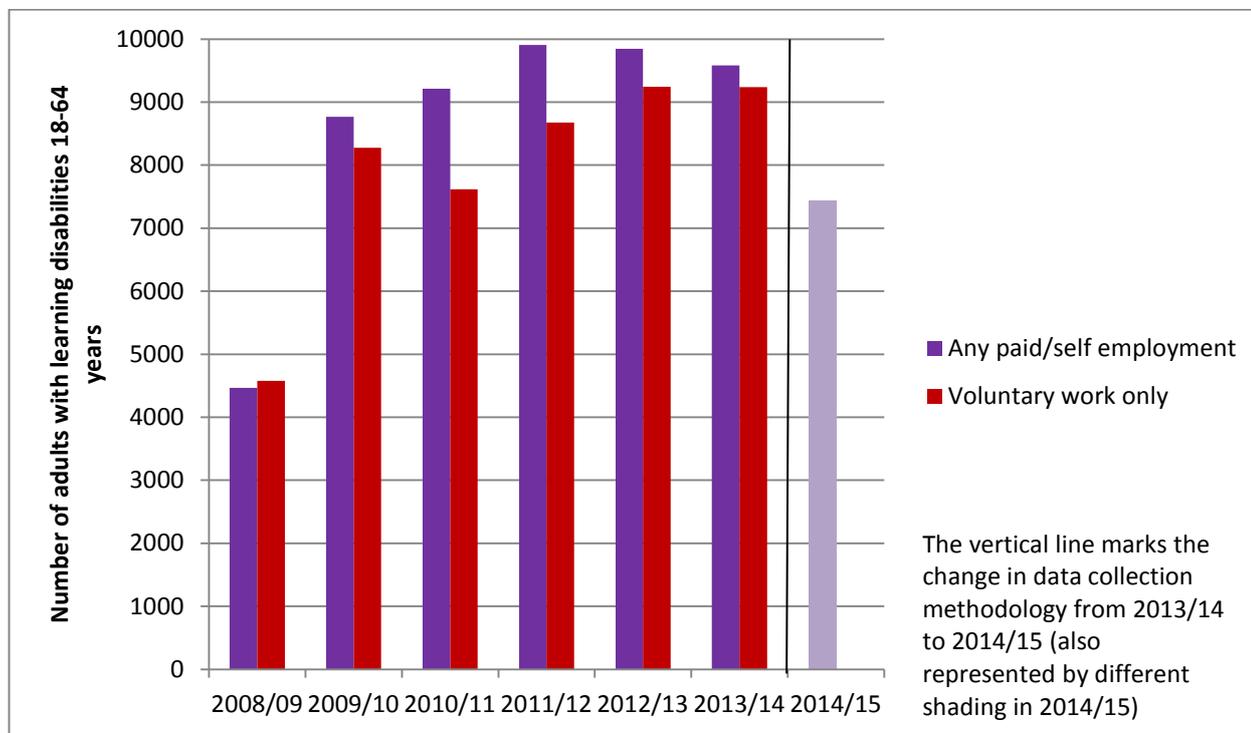
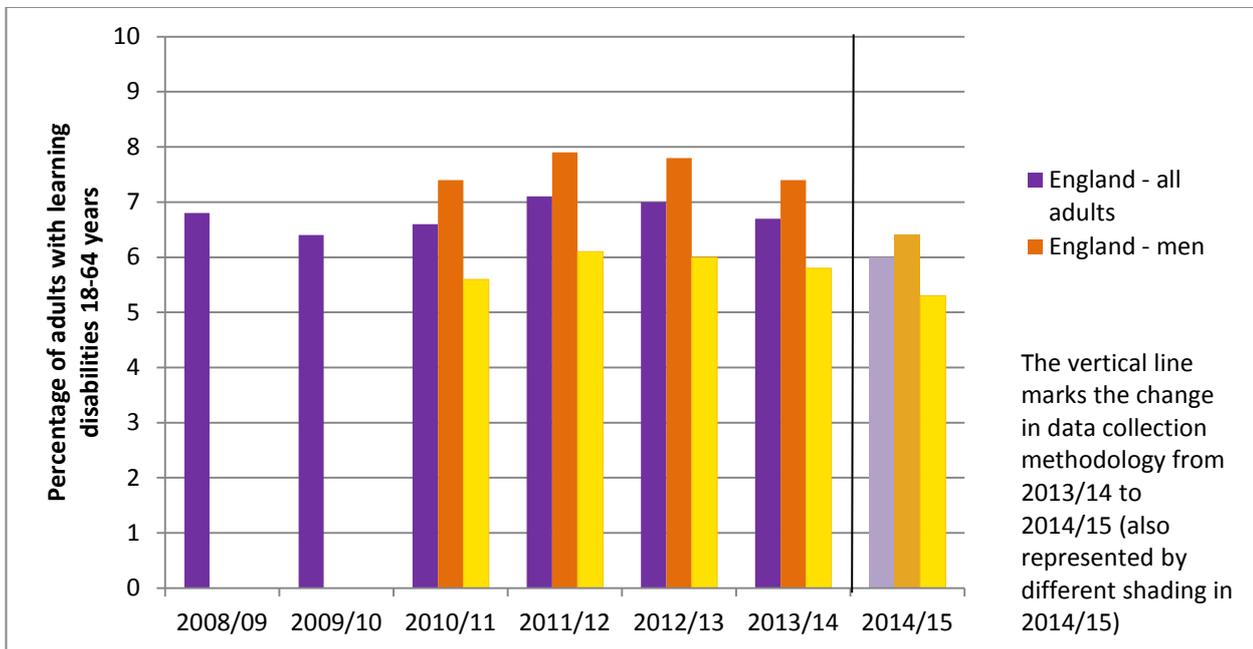


Figure 8.2 below presents information on the percentage of working age adults with learning disabilities (aged 18 to 64 years) known to councils who are engaged in any paid/self employment (see Table 8.2 for more details, including data on regional variations). When interpreting Figure 8.2, it is important to note that the population of adults with learning disabilities counted as known to councils changed from 2013/14 to 2014/15 (see Chapter 7); from 2014/15 this is only adults with a primary support need of learning disabilities receiving long-term social care support from councils.

As Figure 8.2 shows, the overall paid/self employment rate for working age adults with learning disabilities reached a peak at 7.1% in 2011/12, and was at 6.7% in 2013/14. In 2014/15 the employment rate was 6.0%. Figure 8.2 also shows employment rates broken down by gender, with men with learning disabilities consistently reporting employment rates 1.1%-1.8% higher than women with learning disabilities.

Figure 8.2: The percentage of working age adults with learning disabilities (18 to 64 years) known to councils who are in any paid/self employment

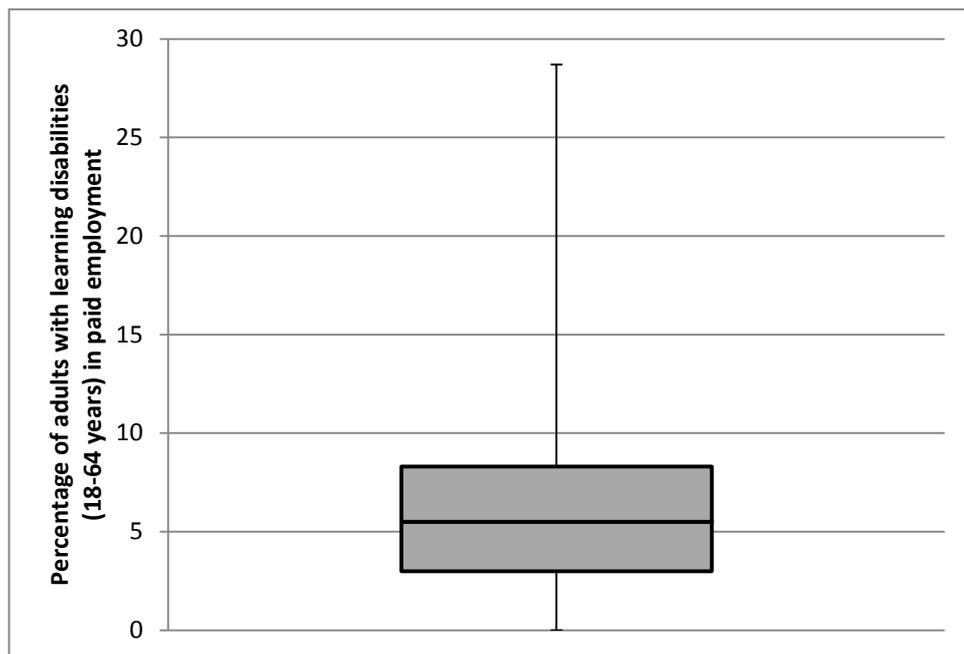


We also investigated geographical variation in reported employment rates, as can be seen in Figure 8.3.

Figure 8.3 shows that in the middle ranked local authority in England, 5.5% of working age adults with learning disabilities were in any form of paid employment, although this varied greatly between local authorities – adults with learning disabilities at the top quartile of councils were more than twice as likely as adults at the bottom quartile to be in paid employment (8.3% vs 3.0%).

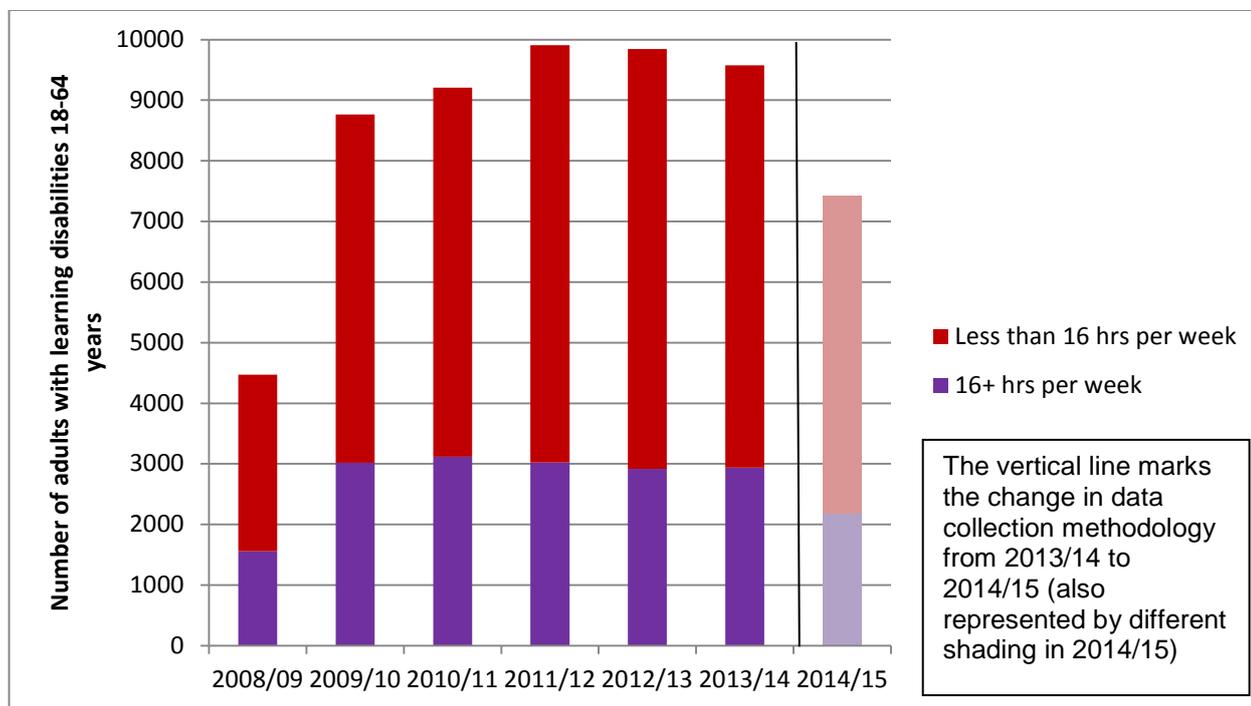
It is important to note the extreme variation of outliers. The ten councils reporting the highest rates of paid employment for people with learning disabilities reported rates from 13.7% upwards, whilst the ten councils reporting the lowest employment rates reported rates of 1.9% or lower; both extremes do represent a range of types of council.

Figure 8.3: Variations across local authorities in the percentage of adults with learning disabilities aged 18 to 64 years in any form of paid employment



The paid/self employment statistics can also be broken down according to the number of hours worked per week. Figure 8.4 below presents this information (see Table 8.1 in the accompanying data tables report) over time up to 2013/14, and for 2014/15. As Figure 8.4 shows, the number of adults with learning disabilities working 16 hours or more per week stayed fairly static from 2009/10 (3,020 people) to 2013/14 (2,940 people); in 2014/15 this figure was 2,185 people. The number of adults with learning disabilities working less than 16 hours per week was 6,635 people in 2013/14 and 5,240 people in 2014/15.

Figure 8.4: Number of working age (18 to 64 years) adults with learning disabilities in paid employment



As part of the new social care data collection², it was also reported for 2014/15 that 11,920 working age adults with learning disabilities were not in paid employment but were actively seeking work, 51,095 people were not in paid employment and not actively seeking work, and the employment status of 53,020 people was unknown.

Safeguarding

For the first time in 2010/11, all local authorities with social services responsibilities were mandated to return statistics concerning the number of vulnerable people aged 18+ who they had been made aware of with regards to potential abuse (Abuse of Vulnerable Adults, AVA). This data collection was repeated in 2011/12 and 2012/13¹. These statistics are fully reported in our previous report, *People With Learning Disabilities in England 2013*², including information on referrals to local authorities for safeguarding issues, the nature of the alleged abuse and the relationship of the alleged perpetrator to the person with learning disabilities, and the outcomes of these referrals.

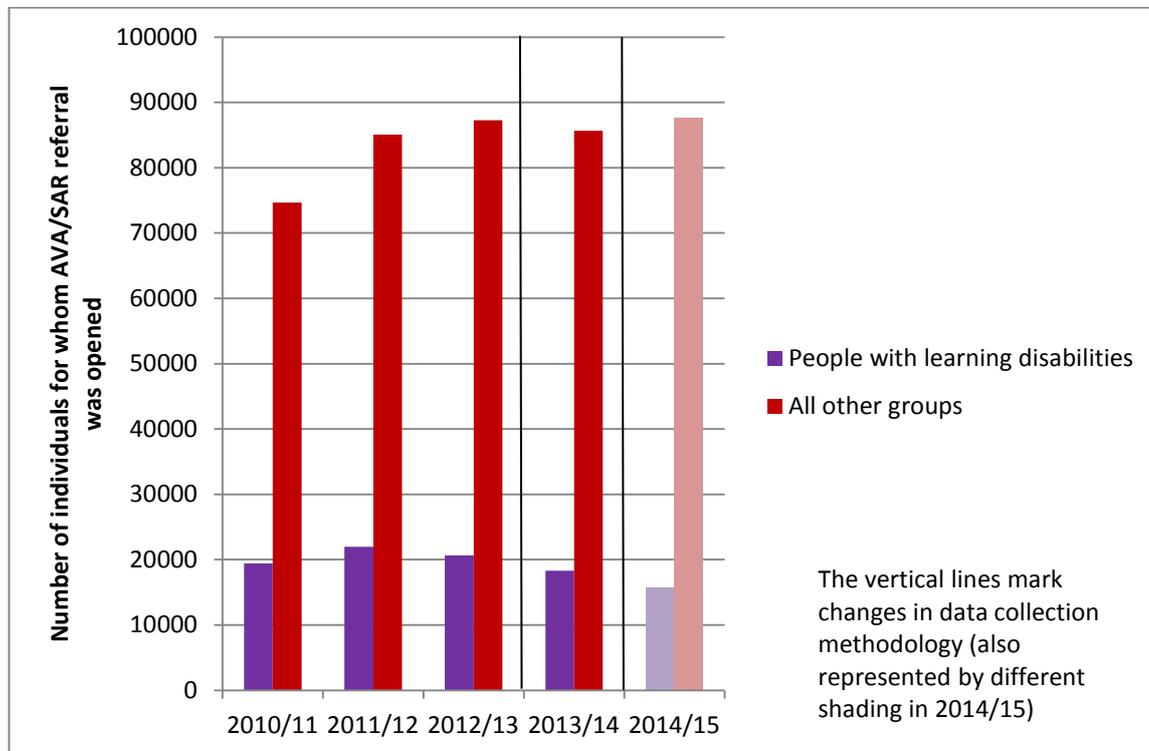
From 2013/14 onwards, AVA returns have been replaced by the Safeguarding adults return³. Publications from both these sets of returns are designated 'experimental statistics', as they relate to new/rapidly developing areas of activity where definitive statistics are still being developed. Due to concerns about the quality of the data, the only data regarding safeguarding that is disaggregated by people with learning disabilities are the number of individuals for whom a safeguarding referral was made in the relevant reporting period. There were other changes to data collection in 2014/15 relating to people being categorised according to primary support reason (see Chapter 7), so the data from 2013/14 to 2014/15 cannot be assumed to be continuous – this is indicated in Figure 9.1 below by a vertical line and different shading for 2014/15.

Figure 9.1 below presents a summary of these data from 2010/11 to 2014/15, for people with learning disabilities and for all other groups (see also Table 9.1 in the accompanying data tables report).

Figure 9.1 shows that safeguarding referrals were made for 15,715 people with learning disabilities in 2014/15. Although there have changes to data collection from 2011/12 to 2014/15, there has been a consistent decrease over this time period. The number of other individuals where safeguarding referrals have been made, while fluctuating, has generally increased over this time period. The proportion of all safeguarding referrals concerning people with learning disabilities was 21% of all referrals in 2010/11 and was 15% of all referrals in 2014/15.

The data table Table 9.1 also provides, for 2013/14 and 2014/15, data on whether safeguarding referrals concerned people previously unknown to the local authority: 8% (2014/15) of safeguarding referrals concerning people with learning disabilities were for people previously unknown to the local authority, compared to 20% (2014/15) of safeguarding referrals for other groups.

Figure 9.1: Number of individuals for whom a safeguarding referral was made in the reporting period: 2010/11 to 2012/13 (AVA) and 2013/14 to 2014/15 (SAR) – people with learning disabilities vs all other groups



Deprivation of liberty safeguards (DoLS)

This chapter summarizes information collected by NHS Digital concerning Deprivation of liberty safeguards (DoLS) applications and outcomes in a series of annual reports¹. NHS Digital states that “The Deprivation of liberty safeguards (DoLS) are a legal framework that exist to ensure that individuals who lack the mental capacity to consent to the arrangements for their care, where such care may (because of restrictions imposed on an individual’s freedom of choice or movement) amount to a ‘deprivation of liberty’, have the arrangements independently assessed to ensure they are in the best interests of the individual concerned.”

Statistics concerning requests for such authorisation, and whether they were granted or not, are available for 2009/10 through to 2014/15. It is worth noting that the recording of disability categories changed slightly after the first quarter of data collection in 2010/11 (that is, at the end of June 2010). Before this time, disability categories were not mutually exclusive and more than one disability category could be entered; after this time only one disability category could be recorded. This is consistent with other data collections which specify a primary need.

The Supreme Court ‘Cheshire West’ judgement in March 2014, broadening the circumstances under which DoLS apply, has had a major impact on the number of DoLS applications and the capacity of local authorities in responding to them. Reflecting this, some of the data for 2014/15 is not provided in ways that are comparable to previous years due to some concerns about the quality of the data.

Figure 10.1 below shows the number of DoLS applications completed by local authorities from 2009/10 to 2014/15 (see Table 10.1 for a more detailed data table). From 2009/10 to 2013/14, the overall number of completed DoLS applications increased steadily from 7,157 applications in 2009/10 to 13,398 applications in 2013/14. However, the number of completed DoLS applications regarding adults with learning disabilities, despite year-on-year fluctuations, stayed reasonably stable over this time period (1,550 applications in 2009/10; 1,403 applications in 2013/14). During this time period, the proportion of completed DoLS applications that concerned adults with learning disabilities dropped from 22% in 2009/10 to 10% in 2013/14.

Following the ‘Cheshire West’ Supreme Court judgement in March 2014, the number of completed DoLS applications increased dramatically, to 62,645 completed applications for all adults in 2014/15. This figure is not broken down according to whether the completed applications concern adults with learning disabilities or not. However, it is important to note that this dramatic increase in DoLS applications resulted in many more DoLS applications not being completed by local authorities by the end of March

2015. Overall, there were 122,775 DoLS applications made in 2014/15 (of which 62,645 were completed by local authorities) – 16,645 (14% of all DoLS applications in 2014/15) of these applications concerned adults with learning disabilities.

Figure 10.1: Number of completed DoLS application 2009/10 to 2014/15 – adults with learning disabilities aged 18+ vs all other adults aged 18+

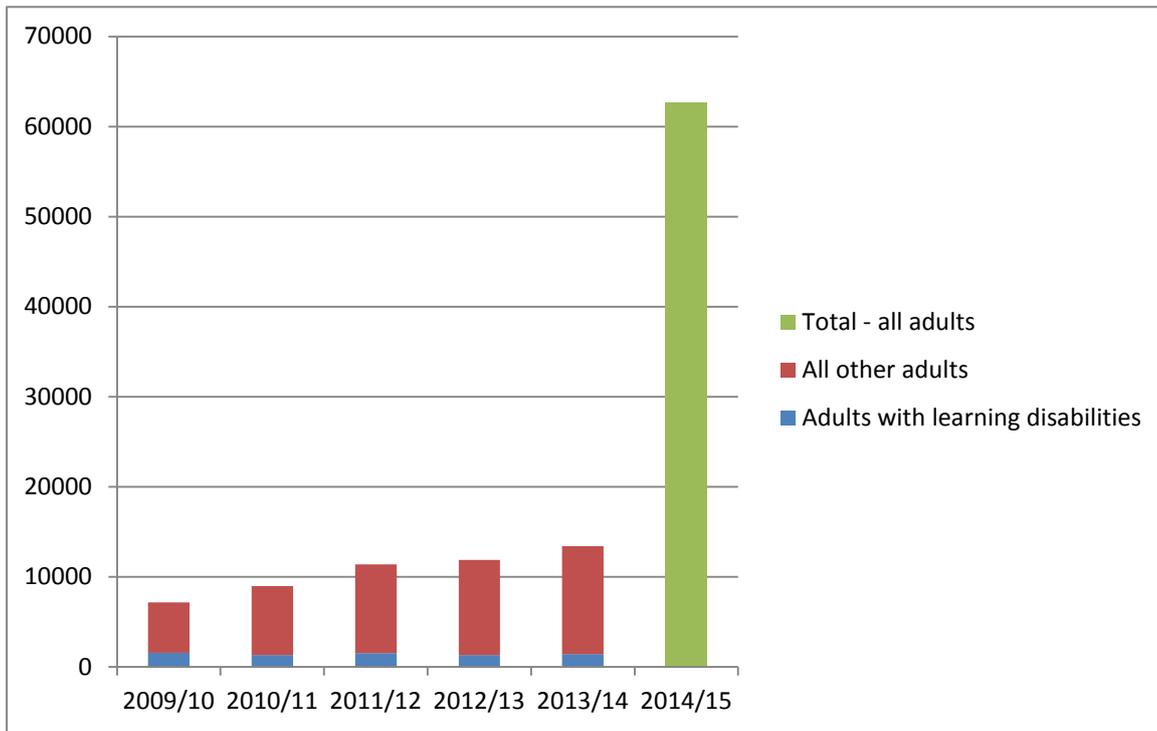


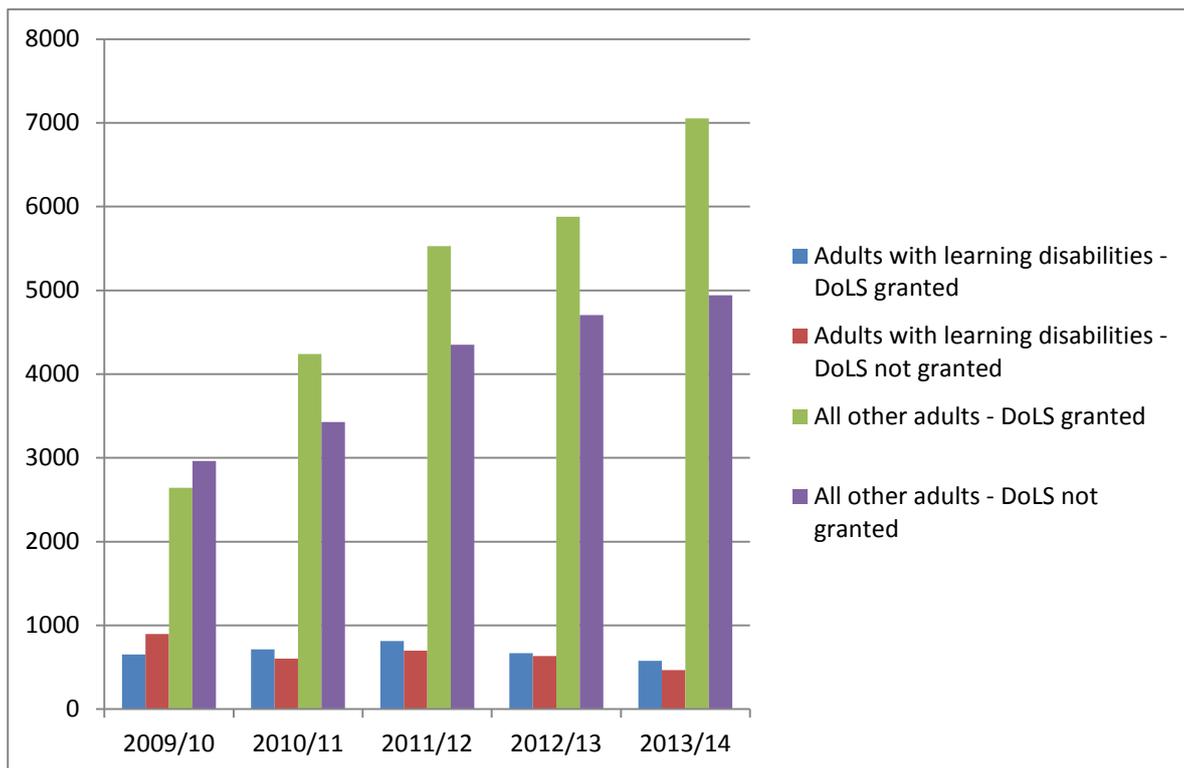
Figure 10.2 below shows the number of completed DoLS applications that were granted vs not granted from 2009/10 to 2013/14 (see Table 10.2 for a more detailed data table). From 2009/10 to 2013/14 the proportion of completed DoLS applications for adults with learning disabilities that were granted increased from 42% in 2009/10 to 54% in 2013/14. For all other adults, the proportion of granted completed DoLS applications also increased, from 47% in 2009/10 to 59% in 2013/14.

In 2014/15 the number of completed DoLS applications that were granted increased dramatically, to 8,795 completed DoLS applications regarding adults with learning disabilities, and 43,400 granted completed DoLS applications regarding other adults. Overall, 10,520 completed DoLS applications were not granted in 2014/15, although this figure is not broken down specifically for adults with learning disabilities (overall 83% of completed DoLS applications were granted in 2014/15) due to concerns about the quality of the data.

For the first time in 2014/15, data concerning granted vs not granted DoLS applications are available for individuals (rather than applications, as a person can be subject to more than one DoLS application in a single year) with and without learning disabilities.

In 2014/15, DoLS applications for 7,820 adults with learning disabilities were granted (90%) and 910 were not granted (10%). For all other adults, DoLS applications for 37,750 adults were granted (81%) and 9,125 were not granted (19%).

Figure 10.2: Number of completed DoLS applications granted and not granted 2009/10 to 2013/14 – adults with learning disabilities aged 18+ vs all other adults aged 18+



Benefits

People with learning disabilities in England, as with other groups of people, are potentially eligible for a range of benefits. Statistics for some but not all of the major benefit types are collected from the Department for Work and Pensions (DWP)¹.

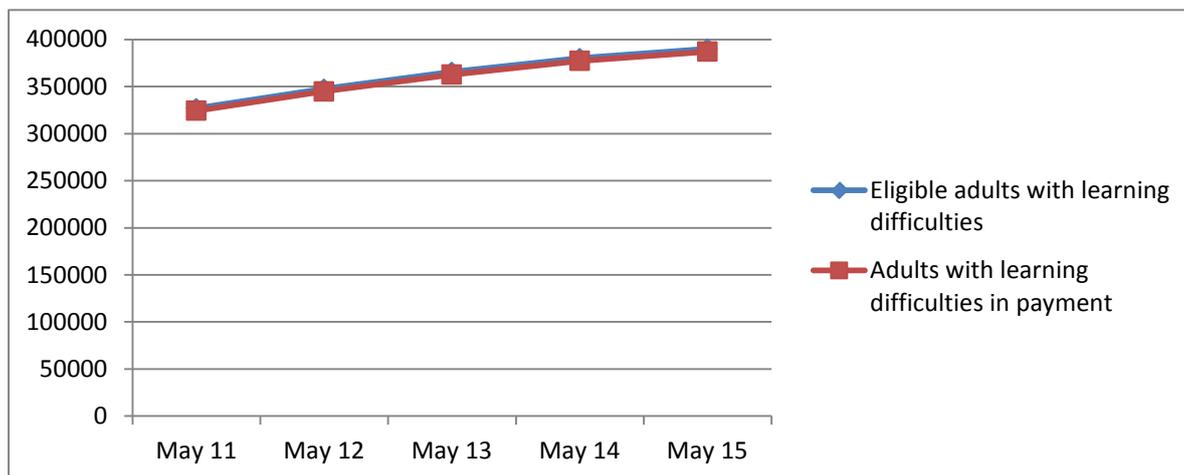
Working age adults

The Department for Work and Pensions (DWP) provides quarterly information on Disability Living Allowance (DLA), that can be disaggregated for adults with 'learning difficulties' in England. The DWP definition of 'learning difficulties' includes 'learning difficulties' (an old generic code still used for pre-2008 cases before more detailed sub-categories were introduced), 'Down's syndrome', 'Fragile X syndrome', 'learning disability – Other/type not known', 'Autism', 'Asperger syndrome', and 'Retts disorder'². This definition is broader than other government departments' definitions of the population of people with learning disabilities.

The Disability Living Allowance (DLA) is a tax-free benefit for disabled people who need help with mobility or care costs. Disability Living Allowance (except for those born before 9 April 1948 and those aged under 16 at the time of application) is due to be replaced by personal independence payments. The DLA consists of two components which are assessed and paid separately, a Care Award (paid at higher, middle and lower rates) and a Mobility Award (paid at higher and lower rates).

Figure 11.1 below (see Table 11.1 for more details) shows the number of people with 'learning difficulties' eligible for and receiving DLA from (May) 2011 (the first year that figures based on a total sample were available) to May 2015.

Figure 11.1: Number of people with learning difficulties in England eligible for and receiving Disability Living Allowance (May) 2011-2015



As Figure 11.1 shows, the number of people with learning difficulties claiming DLA has increased by 4.5% per year from 2011 to 2015, with almost everyone eligible for DLA actually claiming (99%).

DLA consists of two components which are assessed and paid separately. In the publicly available national statistics, figures for people with learning difficulties cannot be disaggregated by both care award and mobility award levels simultaneously. This means that figures by level of care award, for example, report the average total DLA amount (that is, including both Care Award and Mobility Award components) received by people at different levels of Care Award.

In terms of the Care Award component of the DLA in the quarter ending May 2015, 116,580 people with learning difficulties were claiming at the higher rate (average claim of £112.61 per week; £5,855.72 per year), 186,420 people were claiming at the middle rate (£76.53 per week; £3,979.56), 54,350 people were claiming at the lower rate (£54.35 per week; £2,826.20 per year) and 29,710 people were claiming at the 'nil' rate (£29.71 per week; £1,544.92 per year). Claims at the 'nil' rate include people who were assessed as being eligible only for the mobility components of DLA. Using these figures indicates that the estimated annual cost of DLA payments to people with 'learning difficulties' in England for 2015 was approximately £1.62 billion.

Information on the number of people claiming personal independence payments (PIP; a benefit for working age adults with sickness and/or disability replacing the DLA, but with some important differences) is available on a monthly basis for adults with learning disabilities, under the category 'Main Disabling Condition/Psychiatric Disorders/Learning Disability Global'. The DWP report the following numbers of people with learning disabilities claiming PIP, rapidly increasing from 2014 to 2016:

- March 2014: 538 people
- March 2015: 8,233 people
- March 2016: 24,340 people

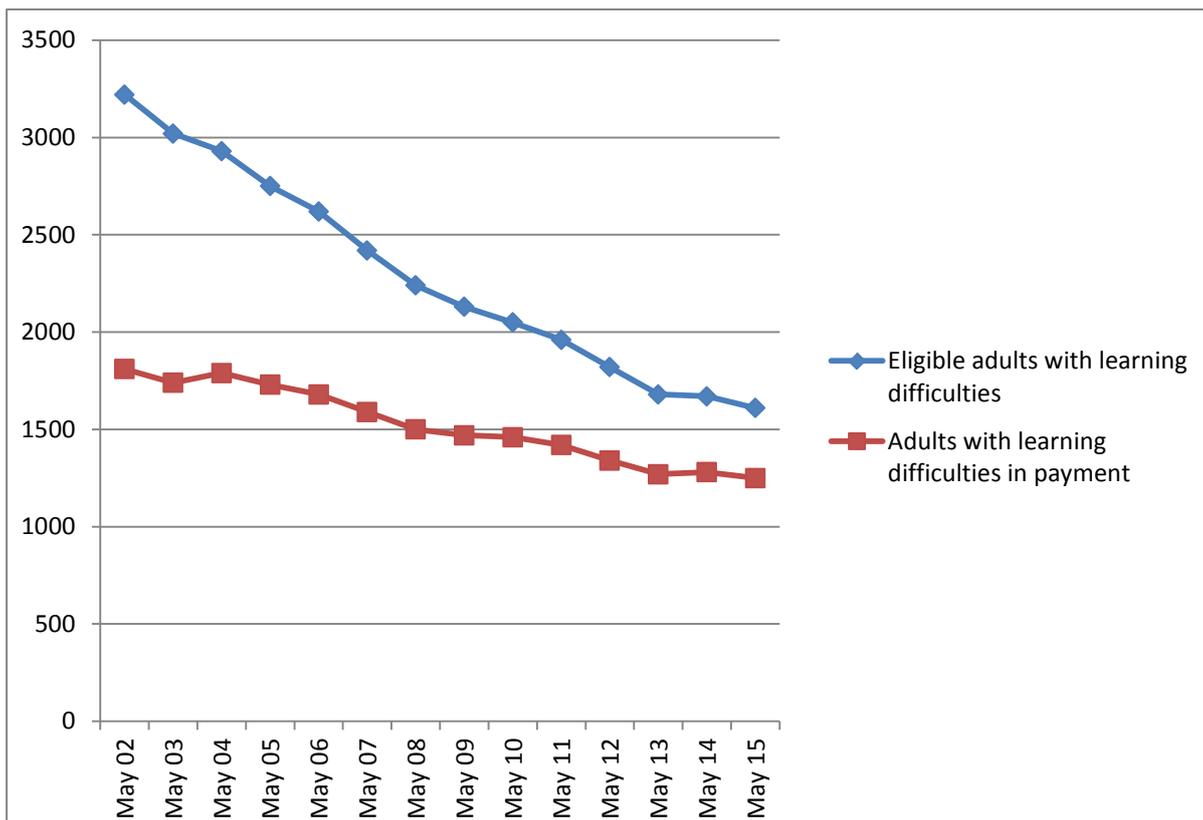
Data on the number of people accessing Job Seeker's Allowance (JSA) for adults of working age who are out of work (or working less than 16 hours per week) and looking for work, is published at the ICD-10 chapter level of 'medical condition/mental and behavioural disorders'³ but cannot be disaggregated further by the specific category relating to learning disabilities. This is the same for Employment Support Allowance (ESA), the successor (with some important differences) to Incapacity benefit. Data concerning Housing benefit, paid to landlords of people in rented housing on low incomes, are not collected in a way that would allow people with learning disabilities to be disaggregated.

Older adults

Attendance allowance is paid to disabled people over the age of 65 to help with personal care. They can be paid at two rates to reflect the level of care required. Figure 11.2 below (see Table 11.1 for details) shows the number of people with ‘learning difficulties’ who are eligible for and actually getting Attendance allowance in England, from the quarter ending May 2002 to the quarter ending May 2015. Eligibility statistics include those who have had their payment temporarily suspended, for example if they are in hospital.

The Department for Work and Pensions (DWP) provides quarterly information on Attendance Allowance (AA) that can be disaggregated for adults with ‘learning difficulties’ in England using the same definitions as for DLA described above.

Figure 11.2: Number of people with learning difficulties in England eligible for and receiving Attendance Allowance (May) 2002-2015



As Figure 11.2 shows, from 2002 to 2015 the number of people with ‘learning difficulties’ who are eligible for Attendance allowance has steadily declined by a compound annual rate of 5.2% per year to 1,610 people in 2015, and the number of those claiming has declined by a compound annual rate of 2.8% per year to 1,250 people in 2015. This may be because people eligible for DLA/PIP before the age of 65 years remain with these benefits into older age rather than transferring to Attendance

allowance (which is only awarded to people with newly identified needs at age 65 or more). The percentage of those eligible for Attendance allowance who are claiming has risen from 56% in 2002 to 78% in 2015.

In the quarter ending May 2015, 350 people with 'learning difficulties' over 65 in England were claiming Attendance allowance at the higher rate (average claim of £81.92 per week; £4,259.84 per year) and 890 people were claiming at the lower rate (£55.05 per week; £2,862.60 per year). Using these figures indicates that the estimated annual cost of Attendance allowance payments to people with 'learning difficulties' for 2015 was approximately £4.0 million.

Family carers

A variety of sources provide information relating to family carers of people with learning disabilities, although there have been major changes to how the data were collected for 2014/15. Carers can be eligible for a range of social care supports for themselves as carers.

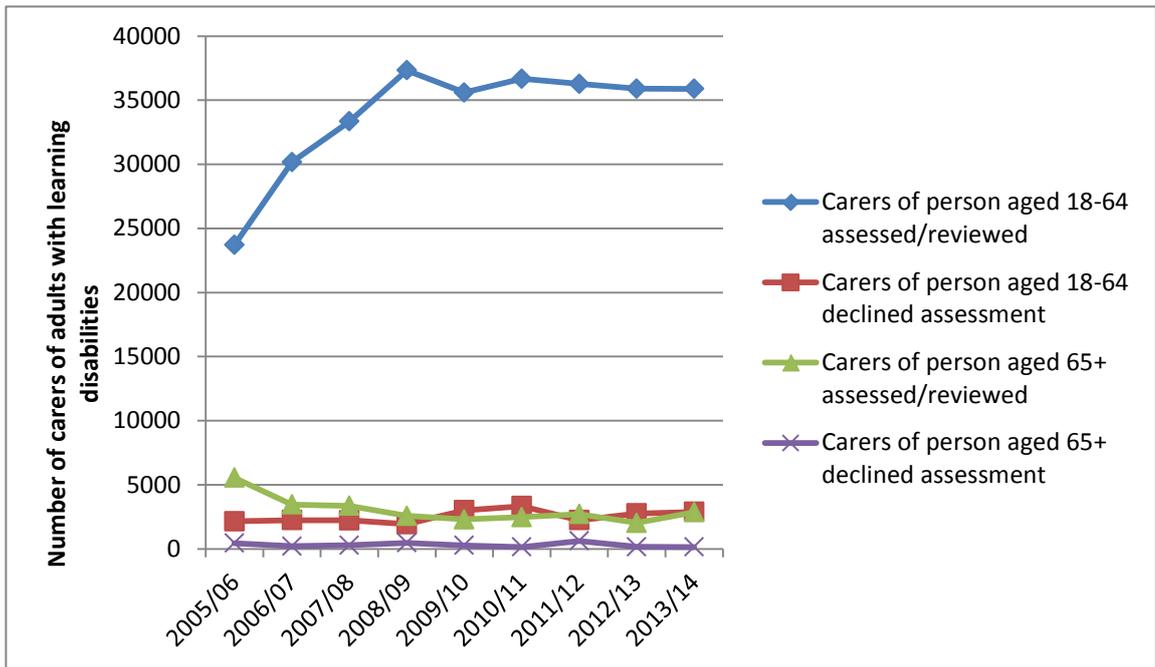
Assessment and support

First, the Health and Social Care Information Centre (now NHS Digital), from 2005/06 to 2013/14, published data on the numbers of assessments or reviews completed for carers (RAP form C1¹) These data can be broken down by the age group of the adult with learning disabilities being cared for, although not by carers' age group. The equivalent SALT data for 2014/15² are not collected in ways that allow a breakdown of family carer assessments/reviews by the need of the person being cared for.

Figure 12.1 (see Table 12.1 for more details) shows that, after an apparent sharp rise in the number of family carers of adults with learning disabilities aged 18 to 64 being assessed/reviewed from 2005/06 to 2008/09, the number of family carers of adults with learning disabilities either being assessed/reviewed or declining an assessment has stayed fairly static.

In 2013/14, 38,755 assessments/reviews were offered to family carers of adults with learning disabilities aged 18 to 64 years, of which 93% were taken up. This represents 74% of households where an adult with learning disabilities aged 18 to 64 years was reported to be in settled accommodation with family or friends (see Chapter 7). For family carers of adults with learning disabilities aged 65 years or more, 3,000 assessments/reviews were offered, of which 95% were taken up.

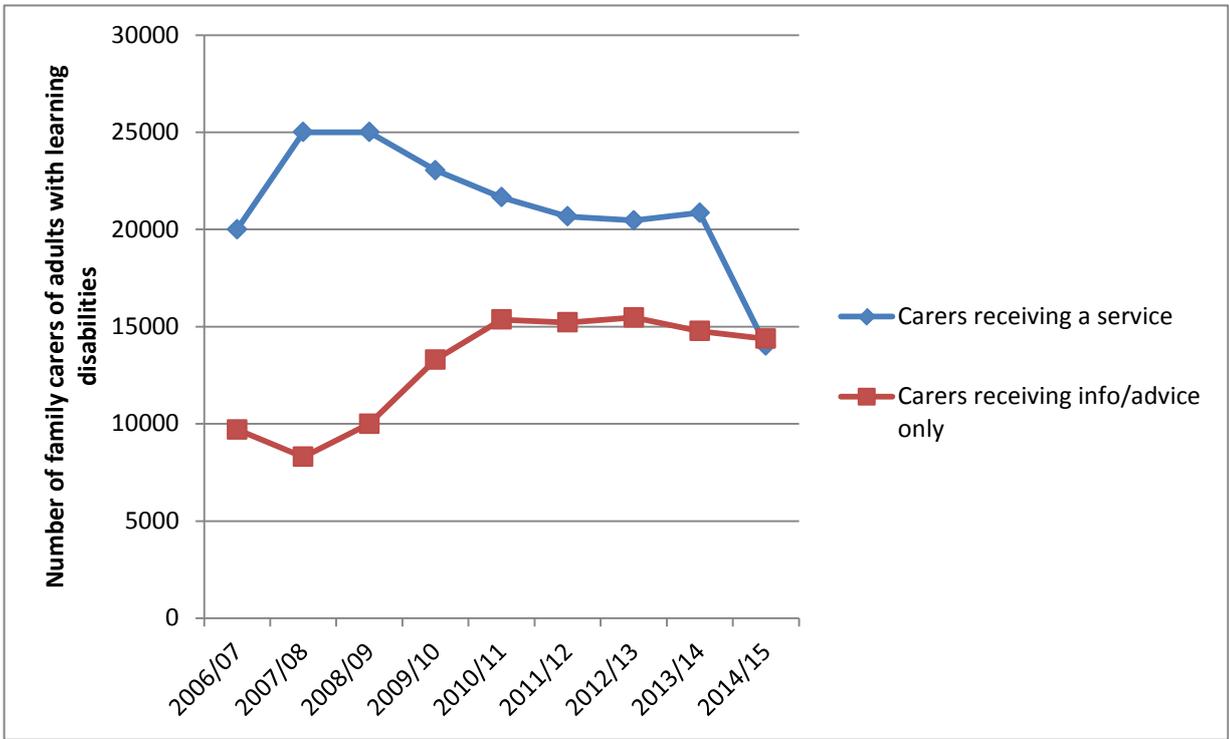
Figure 12.1: The number of family carers of adults with learning disabilities receiving or declining an assessment or review 2005/06 to 2013/14



Second, Figure 12.2 below (see Table 12.2 for a more detailed data table) shows the number of family carers of adults with learning disabilities either receiving a carer service or receiving information/advice/signposting/universal service only. Data collection for these variables were consistent from 2006/07 to 2013/15. During this time period, there was an overall reduction in the number of family carers of an adult with learning disabilities getting a service for themselves as carer, with the number of family carers getting information/advice/signposting etc plateauing from 2010/11.

The SALT data return for 2014/15 reports that, of the 14,015 family carers getting a service: 7,675 carers (55%) were getting a direct payment only; 2,010 carers (14%) were getting a service with a part direct payment; 2,065 carers (15%) were getting a council-managed personal budget; and 2,265 carers (16%) were getting council support not in the form of a direct payment/personal budget. For 9,410 family carers (67%), part of their support included a service that involved the cared for person. A further 14,375 family carers were getting support in the form of information/advice/signposting or a universal service only, and finally, 10,265 family carers were getting no direct support.

Figure 12.2: The number of family carers of adults with learning disabilities receiving carer services or information/advice/universal services/signposting only 2006/07 to 2014/15



Family carer experiences

The Personal Social Services Survey of Adult Carers in England is a biennial survey, undertaken by councils, which took place in its current format for the first time in 2012/13 and was repeated in 2014/15³. The survey is published by NHS Digital and includes carers aged 18+ who are caring for someone aged 18+ who is in receipt of services funded (in whole or in part) by Social Services. The experiences of the carers of children or child carers are not included in this dataset.

In 2014/15, in total 56,220 of 128,356 family carers responded to the survey (a 43.8% response rate). For 6,160 (11.0%) of these family carers the primary support need of the cared for person was a learning disability, with a further 3,537 cared for people (6.3%) reported by family carers to have a learning disability/difficulty alongside a different primary support need. Cared for people who had a primary support need of learning disability were also reported by family carers to have other needs, such as: physical disability (35.4% of cared for people), a mental health problem (23.1%), a long standing illness (21.6%), sight and/or hearing loss (16.8%), problems linked to ageing (5.5%), a terminal illness (1.7%), alcohol or drug dependency (0.6%). Adults with a primary support need of learning disability were relatively young with over half of people (54%) aged 18 to 34 years, over a third of people (38.1%) aged 35 to 64 years, and 7.8% of people aged 65 years or more.

Overall, 2% of all family carers reported that they had learning disabilities/difficulties. Of the carers of people with a primary support need of learning disability, 6% of family carers reported that they also had learning disabilities/difficulties.

For carers where the primary support need of the person they care for was learning disabilities or difficulties:

- over half (51.4%) spend 100 or more hours a week caring for that person, compared with 38.1% for all carers in England
- 74.3% of carers of a person with learning disabilities had been in a caring role for more than 20 years, compared with an average of 20.1% for all carers in England
- 30.2% were not in paid employment because of their caring responsibilities, compared with 20.5% for all carers in England
- for 87.4% of carers the person they care for usually lives with them rather than somewhere else, compared with an average of 73.0% for all carers in England

In terms of the experiences of family carers of an adult with learning disabilities:

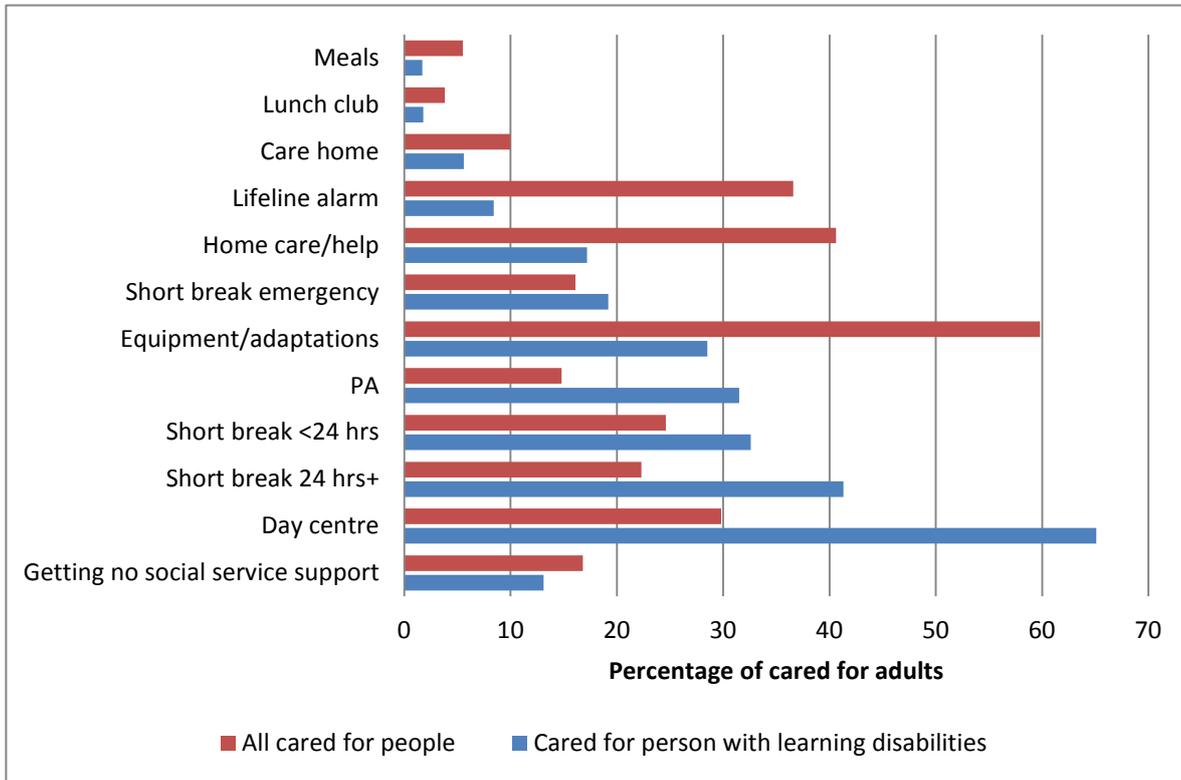
- nearly a quarter (24.6%) of family carers reported spending as much time as they wanted doing what they valued or enjoyed, 63.0% spent some but not enough time doing what they valued or enjoyed and 12.4% didn't do anything they valued or enjoyed with their time
- over a quarter of family carers reported having as much control over their daily life as they wanted (28.2%), 60.3% reported having some but not enough control and 11.5% reported having no control over their daily life
- over a half (57.3%) reported they had enough time to look after themselves (eg sleep, diet), with 29.0% reporting being able to do this sometimes and 13.7% reporting neglecting themselves
- most family carers (80.7%) reported having no worries about their personal safety, 17.5% reported having some worries and 1.7% were extremely worried about their personal safety
- around two-fifths of family carers (41.5%) reported having as much social contact as they wanted, 45.1% reported having some but not enough social contact, and 13.5% reported feeling isolated, with little/no social contact
- overall, these experiences were broadly similar to experiences reported by other family carers in the survey

Access to support or services

For family carers of people with learning disabilities, carers reported the services used by the person they were caring for in the previous 12 months. The percentage of cared

for adults using several types of social care support, compared to cared for adults generally, is presented below in Figure 12.3.

Figure 12.3: Percentage of cared for adults with learning disabilities and cared for adults overall using various types of social care support



As Figure 12.3 shows, for family carers of people with a primary support need of learning disability 13% of cared for people were reported not to have received any social services support at all in the past 12 months, compared to 17% of cared for people overall.

In terms of specific services, cared for adults with learning disabilities were more likely than cared for adults overall to have used: a day centre (65% vs 30%), a short break for 24 hours or more (41% vs 22%), a short break for less than 24 hours (33% vs 25%), an emergency short break service (19% vs 16%) and a personal assistant (32% vs 15%). In contrast, cared for adults with learning disabilities were less likely than cared for adults overall to have used: equipment or adaptations (29% vs 60%), home care (17% vs 41%), a lifeline alarm (8% vs 37%), permanent residence in a care home (6% vs 10%), a lunch club (2% vs 4%), and a meals service (2% vs 6%). These differences are likely to reflect the different needs of adults with learning disabilities and their families compared to other groups of adults being cared for by family members.

In terms of support for themselves as family carers of people with learning disabilities in the previous 12 months:

- almost half reported receiving information or advice (46.2% vs 53.9% of family carers generally)
- over a quarter reported accessing carers' groups (26.8% vs 30.8% generally)
- very few reported receiving carer training (5.0% vs 5.5% generally)
- very few reported receiving support to stay in employment (4.7% vs 3.4% generally)

Over two fifths of family carers of people with learning disabilities reported that it was very/fairly easy to find information/advice (42.0%), with over a quarter (28.4%) reporting that this was difficult and a similar proportion (29.5%) reporting that they had not tried to find information/advice in the past 12 months.

A majority of family carers (58.0%) reported that the information/advice they had received was very/quite helpful, with around one in ten carers (11.1%) reporting the information/advice to be quite/very unhelpful and almost a third of carers (30.9%) reporting not receiving any information/advice in the last 12 months.

Family carers were also asked if they felt involved/consulted in discussions about the support of the person they were caring for. Almost a third (32.5%) reported always being involved/consulted; almost a half (43.3%) reported being usually/sometimes involved/consulted; and 5.4% of family carers reported never being involved/consulted. A substantial minority (18.4%) of family carers of people with learning disabilities reported that there hadn't been any discussions they were aware of.

Overall, family carers of adults with learning disabilities reported slightly lower levels of satisfaction with the support received than other family carers, in terms of being: extremely/very satisfied (38% vs 41%), quite satisfied (34% vs 33%), neither satisfied nor dissatisfied (14% vs 15%), or quite/very/extremely dissatisfied (17% vs 11%).

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