



Public Health
England

Protecting and improving the nation's health

People with Learning Disabilities in England 2013

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Summary

Information on the characteristics of people with learning disabilities, the services and supports they use and their carers is collected by several government departments and made publically available through a number of diverse channels. The aim of this report is, within a single publication, to provide a concise summary of this information for people with learning disabilities in England and to provide links to key data collections.

In each area we have reported the most recent data that is available. In most instances this relates to activity in 2012 to 2013. Wherever possible we have also included data from previous years in order to identify trends over time. This report is the fourth in an annual series.

The number of people with learning disabilities in England

On the basis of estimates obtained 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, we estimate:

- in England in 2013 there are 1,068,000 people with learning disabilities. This includes:
 - 224,930 children (identified at School Action Plus or statements in DfE statistics as having either a primary or secondary Special Educational Need associated with learning disabilities);
 - 900,900 adults, of who:
 - 177,389 (20%) were eligible for annual health checks
 - 206,132 (23%) were known to GPs as people with learning disabilities
 - 429,530 (48%) were recorded by Department of Works and Pensions as being eligible to receive either Disability Living Allowance or Attendance Allowance

Mortality

In the absence of national mortality review data, the most up to date information we have on the mortality of people with learning disabilities is:

- the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) found that men with learning disabilities died on average 13 years younger than men in the general population and women 20 years younger
- half of local partnership boards in their responses to the 2012 to 2013 self-assessment framework were able to provide data about people with

learning disabilities sufficient to permit calculation of crudely standardized mortality ratios (SMRs). Data submitted suggested that on average the death rate for people with learning disabilities is a little more than twice that in the general population

- the median age at death of people identifiable as having learning disabilities in death certificates has risen steadily from 2008 to 2012 from 54 to 58 years

Health services

Information collected by the Information Centre for Health and Social Care on health services utilised by people with learning disabilities indicates that:

- GPs are recognising more people with learning disabilities on their practice lists, 4.5 in every thousand in 2011 to 2012
- marked progress has been made from financial year 2008 to 2009 to financial year 2011 to 2012 in the delivery of health checks to people with learning disabilities, with just over half (53%) of eligible adults receiving a health check in 2011 to 2012
- in 2011 to 2012 there were 104,709 attended outpatient appointments with clinical specialists who have a primary expertise in learning disabilities, up from 83,719 in 2010 to 2011

Education

Information collected by the Department for Education (DfE) on the education of children with Special Educational Needs (SEN) associated with learning disabilities shows that:

- overall, approximately 180,000 children in England were identified in 2012 to 2013 as having a primary SEN associated with learning disabilities. Of these, nearly 4 out of 5 had a moderate learning difficulty (MLD), 1 in 6 had severe learning difficulties (SLD) and 1 in 20 had profound multiple learning difficulties (PMLD). An additional 46,000 children were identified as having a secondary SEN associated with learning disabilities
- over 70,000 children in England have a statement of SEN and a primary SEN associated with learning disabilities. Of these, just under half had MLD, over one third had SLD and 1 in 8 had PMLD
- between 2009 to 2010 and 2012 to 2013, the number of children identified as having a primary SEN associated with learning disabilities reduced by 15%, even though the total number of children on school rolls increased by 2%
- SEN associated with learning disabilities is more common among boys, children from poorer families and among some minority ethnic groups

- overall, 88% of children with MLD, 22% of children with SLD and 17% of children with PMLD are educated in mainstream schools. These rates are declining among children with learning disabilities, especially children with SLD
- there was substantial variation across local authorities in the percentage of children with a primary SEN (School Action Plus or with statements) associated with learning disabilities who were placed in mainstream schools
- for children with SLD: the 10% of councils making most use of mainstream schools placed 44% or more of children in mainstream schools; the 10% of councils making least use of mainstream schools placed less than 8% of children in mainstream schools
- for children with PMLD: the 10% of councils making most use of mainstream schools placed 32% or more of children in mainstream schools; the 20 councils (13%) making least use of mainstream schools placed no children with PMLD in mainstream schools
- children with a primary SEN associated with learning disabilities were more likely than other children to be absent from school and to be excluded from school (including permanent exclusion)

Children's social care

Information from the DfE indicates that:

- at 31 March 2013 24,686 children in England were identified as being Children in Need and having a disability associated with learning. This represents 0.22% of the total child population in England. Variation by local authority was substantial. The number of Children in Need who had a disability associated with learning increased by 3.8% between 2012 and 2013
- at 31 March 2013 4,470 children with SEN associated with learning disabilities had been looked after continuously for at least 12 months by the local authority. The number of looked after children with SEN associated with learning disabilities increased by 10.1% between 2012 and 2013
- nearly 1 in 3 of 'looked after' children (those in the care of the local authority) have SEN associated with learning disabilities
- the majority of looked after children with SLD (87%) and PMLD (90%) were attending special schools. The majority of looked after children with MLD (73%) were attending mainstream schools
- the risk per 1,000 children of being looked after continuously for at least 12 months by the local authority as of March 31 2013 was: 6 for all children, 22.3 for children with MLD, 31.9 for children with SLD and 39.9 for children with PMLD

Adult social care

This section summarises information collected by the Information Centre for Health and Social Care on social care services utilised by adults with learning disabilities.

Regarding non-healthcare accommodation for adults with learning disabilities in England:

- in 2012 to 2013 local authorities reported that 74% of the 140,015 adults with learning disabilities known to them were living in some form of settled accommodation, with the most common type of accommodation being settled mainstream housing with family/friends (50,930 people)
- in 2012 to 2013 there were 31,150 adults aged 18+ with learning disabilities in local authority funded independent sector residential care; 1,945 adults in local authority staffed residential care; 1,930 adults in nursing care and 4,005 adults in adult placement schemes
- from 2011 to 2012 to 2012 to 2013 with the exception of adult placements (increase 1.1%), there were decreases in the number of adults with learning disabilities in all other forms of residential care (decrease 3.5%)
- in 2012 to 2013 local authority gross current expenditure relating to residential services for adults with learning disabilities aged 18 to 64 years was:
 - £2 billion on residential care (a 0.9% real terms decrease from 2011 to 2012)
 - £867.5 million on supported/other accommodation (a 13.6% real terms increase from 2011 to 2012)
 - £91.1 million on nursing care (a 5.9% real terms increase from 2011 to 2012)
 - £108.8 million on Supporting People (a 12.5% real terms decrease from 2011 to 2012)

Regarding community social care services in England:

- in 2012 to 2013 local authorities reported 114,265 adults with learning disabilities aged 18+ using some form of social care community service (with small but consistent year-on-year increases from 2005 to 2006)
- regarding day services, in 2012 to 2013 there were 51,300 adults with learning disabilities using local authority funded day services (with small but consistent year-on-year decreases from 2005 to 2006). In 2012 to 2013, local authorities spent £681.5 million on day services for adults with learning disabilities aged 18 to 64 years, a real terms decrease of 4.5% from 2011 to 2012
- regarding home care services, in 2012 to 2013 there were 42,200 adults with learning disabilities using local authority funded home care services (with numbers virtually static from financial year 2010 to 2011 to financial year 2012 to 2013). In 2012 to 2013, local authorities spent £655.5 million

on home care services for adults with learning disabilities aged 18 to 64 years (expenditure static from 2011 to 2012)

- regarding professional support, in 2012 to 2013 there were 22,400 adults with learning disabilities using local authority funded professional support, a decrease of 37% from 2010 to 2011. No specific data is available on local authority spending for professional support
- regarding equipment and adaptations, in 2012 to 2013 there were 9,860 adults with learning disabilities receiving some support for equipment and/or adaptations (with numbers virtually static from financial year 2010 to 2011 to financial year 2012 to 2013). In 2012 to 2013, local authorities spent £4.5 million on equipment and adaptations for adults with learning disabilities aged 18 to 64, a real terms decrease of 29% from financial year 2010 to 2011 to financial year 2012 to 2013
- regarding meals, in 2012 to 2013 450 adults with learning disabilities received a local authority funded meals service (with consistent year-on-year decreases from 2005 to 2006), with local authorities spending £0.5 million on meals services for adults with learning disabilities aged 18 to 64
- in 2012 to 2013 21,700 adults with learning disabilities were using some form of local authority funded 'other' service, a decrease of 5% from 2011 to 2012. Local authorities spent £144.7 million on 'other' services for adults with learning disabilities aged 18 to 64 in 2012 to 2013, a real terms decrease of 14% from 2011 to 2012 to 2012 to 2013

Regarding social care assessments and reviews in England:

- in 2012 to 2013 12,615 new adult clients with learning disabilities had a completed assessment, with numbers fluctuating year-on-year but fairly static from 2009 to 2010
- in 2012 to 2011; 92,960 existing adult clients with learning disabilities had a completed review, a decrease of 9% from 2010 to 2011
- in 2012 to 2013 local authorities spent £292.6 million on assessment and care management for adults with learning disabilities aged 18 to 64, a real terms increase of 1% from 2011 to 2012

Regarding direct payments and self-directed support in England:

- in 2012 to 2013 78,820 adults with learning disabilities were reported by local authorities to be making use of a direct payment and/or self-directed support, an increase of 85% from 2010 to 2011
- in 2012 to 2013 49,035 of these 78,820 adults (62%) were using self-directed support in the form of council-services only, an increase of 148% from 2010 to 2011
- in 2012 to 2013 18,600 of these 78,820 adults (24%) were using direct payments only (either as part of self-directed support or separately), an increase of 2% from 2010 to 2011

- in 2012 to 2013 local authorities spent £385 million on direct payments for adults with learning disabilities aged 18 to 64 years, a real terms increase of 48% from 2010 to 2011

Regarding service user experiences of social care in England:

- in the personal social services adult social care survey (2011 to 2012 and 2012 to 2013), 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 any other group of people using social care. A range of factors, including methodological factors, are likely to account for these differences

Employment

The Health and Social Care Information Centre reports data from local authority returns on the employment of 18 to 64 year-old adults with learning disabilities:

- in 2012 to 2013 7% of working age adults with learning disabilities (9,845 people) were reported to be in some form of paid or self-employment
- most people (70.3%) in paid/self-employment worked for less than 16 hours per week
- men were more likely to be in paid/self-employment than women (men 64% of adults with learning disabilities in paid/self-employment) and were more likely to be working 30+ hours per week than women (men 79.5% of those working 30+ hours per week)
- employment rates varied considerably across local authorities, ranging from 0% to 20.4% of working age adults with learning disabilities known to local authorities
- an additional 9,245 working age adults with learning disabilities were engaged in unpaid voluntary work only

Abuse of vulnerable adults

The Health and Social Care Information Centre report returns by local authorities on the number of vulnerable adults referred due to concerns about possible abuse:

- in 2012 to 2013 there were 20,660 referrals concerning adults with learning disabilities, 92% of which concerned adults aged 18 to 64 years (for other groups of vulnerable adults only 26% concerned adults with 18 to 64)
- the number of referrals concerning adults with learning disabilities increased by 13% from financial year 2010 to 2011 to financial year 2011 to 2012, but then decreased by 6% from financial year 2011 to 2012 to financial year 2012 to 2013. In contrast, the number of referrals concerning other groups of vulnerable adults increased consistently by 14% from financial year 2010 to 2011 to financial year 2011 to 2012, and again by 3% from financial year 2011 to 2012 to financial year financial year 2012 to 2013

- for adults with learning disabilities, numbers of repeat referrals rose from 4,145 in 2010 to 2011 (21.3% of learning disabilities referrals) to 5,215 in 2012 to 2013 (25.2% of learning disabilities referrals)
- of the 15,305 reported completed referrals concerning adults with learning disabilities aged 18 to 64 years (data broken down by client group for adults aged 65 or more is not available) in 2012 to 2013 allegations of abuse were substantiated in over a third of cases (35.3%) and not substantiated in just over a quarter of cases (27.1%), with the outcome of just over a further quarter of cases (26.4%) reported as not determined/inconclusive
- for adults with learning disabilities aged 18 to 64 years, the most common type of alleged abuse was physical abuse (36%), followed by neglect (18.8%), emotional/psychological abuse (17.9%), financial abuse (13.2%) and sexual abuse (9.2%)
- for adults with learning disabilities aged 18 to 64 years in 2012 to 2013 the most common alleged perpetrator was a member of social care staff (29.6%), followed by another vulnerable adult (20.6%), another family member (excluding partners, 14.2%) and the perpetrator not being known (11.2%). From financial year 2010 to financial year 2011 to 2012 to 2013, there was a decrease of 5.9% in the proportion of alleged perpetrators being identified as social care workers
- for adults with learning disabilities aged 18 to 64 years in 2012 to 2013 over half of all referrals were made by social care staff (55.6%); the next most common source of referrals were health staff (11%) followed by a diverse range of referral sources

Deprivation of Liberty Safeguards assessments

This section summarizes information collected by the NHS Information Centre from Primary Care Trusts (PCTs) and Local Authorities concerning Deprivation of Liberty Safeguards (DoLS) assessments:

- in 2012 to 2013 1,304 completed applications were made under DoLS concerning adults with learning disabilities. Most of these (79.6%) were made by local authorities
- 669 of the applications (51.3%) were granted, a slightly smaller proportion to those granted concerning other adults (55.5%)
- DoLS applications concerning adults with learning disabilities decreased from 1,513 in 2011 to 2012 to 1,304 in 2012 to 2013
- this is in contrast to DoLS applications for other adults, which rose from 9,880 in 2011 to 2012 to 10,583 in 2012 to 2013

Benefits

The DWP reports quarterly data on the following benefits – the data here specifically concerns people with learning disabilities.

In the quarter ending May 2013:

- 424,160 people were receiving Disability Living Allowance. From 2002 to 2013, the number of people claiming Disability Living Allowance has increased by 5.7% per year
- the estimated annual cost of Disability Living Allowance payments in 2013 was £1.64 billion. This has increased 8.4% from estimated 2012 costs
- 1,510 people were claiming Attendance Allowance. From 2002 to 2013, the number of people eligible for Attendance Allowance decreased by 6% per year. The number of people claiming Attendance Allowance has decreased by 3.7% per year
- the estimated annual cost of Attendance Allowance payments in 2013 was £4.8 million. This has decreased 4.2% from estimated 2012 costs

Family carers

A variety of sources provide information relating to family carers of people with learning disabilities. Health and Social Information Centre statistics, based on returns from local authorities, report that:

- in 2012 to 2013 a total of 40,845 carers were offered an assessment or review. Of these, 37,930 (93%) took place.
 - Of those that took place:
 - 22,285 (59%) involved a joint assessment or review with the person with learning disabilities
 - 5% were for an adult with learning disabilities who was 65 years old or older
 - after an assessment took place, 35,930 (95%) carers received services or information:
 - 20,465 (54%) of carers received services (eg short breaks)
 - 15,465 (41%) only received information and advice. This has increased from 23% in 2007/08, an average increase of 3.5% per year
- the personal social servicesSurvey of adult carers in England (2012 to 2013) found that:
 - 48% of carers of an adult with learning disabilities spend 100 or more hours a week caring for that person
 - 73% of carers of an adult with learning disabilities had been caring for more than 20 years
 - 29% were not in paid employment because of their caring responsibilities
 - for 88% of carers the person they care for usually lives with them

Rates of reported carer dissatisfaction are low. Of carers of people with learning disabilities, 11% said that they are fairly, very or extremely dissatisfied. This compares with 9% for all carers in England.

1. Introduction

Information on the characteristics of people with learning disabilities, the services and supports they use and their carers is collected by several government departments and made publically available through a number of diverse channels. The aim of this report is 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 a comprehensive national census of activity at either a given point in time or over a given period. They are not based on samples of people with learning disabilities (representative or otherwise). We have clearly indicated where this is not the case.

In each area we have reported the most recent data that is available. In most instances this relates to activity in 2012 to 2013. 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 fourth in an annual series.

Enquiries about the information contained in this report should be directed to info@ihal.org.uk

2. The number of people with learning disabilities in England

Summary

On the basis of estimates obtained 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, we estimate:

- In England in 2013, there are 1,068,000 people with learning disabilities. This includes:
 - 224,930 children (identified at School Action Plus or statements in DfE statistics as having either a primary or secondary SEN associated with learning disabilities)
 - 900,900 adults, of whom:
 - 177,389 (20%) were deemed eligible for annual health checks
 - 206,132 (23%) were known to GPs as people with learning disabilities and
 - 429,530 (48%) were recorded by the DWP as being eligible to receive either Disability Living Allowance or Attendance Allowance

Introduction

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

Information is collected by the DfE on the SEN of all children in maintained schools and non-maintained special schools (see Chapter 5 for more detail). Children not included in this process include children being educated at home and children educated in independent (non-state funded) mainstream schools and profit making independent special schools. Three types of SEN, when combined, are approximately equivalent to learning disabilities: MLD; SLD and PMLD.

In 2012 to 2013 224,930 children were identified at School Action Plus or above in DfE statistics as having either a primary or secondary SEN associated with learning disabilities. This is equivalent to 2.7% of children attending these schools, an estimate of the prevalence of learning disabilities that is broadly consistent with the results of epidemiological research.¹⁻³

Adults with learning disabilities

Three approaches can be taken to estimating 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
- 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. The most comprehensive information of this kind is collected annually from councils with social services responsibilities in relation to the number of adults who have received social care services in any given year and is used to determine the number of adults deemed eligible for annual health checks (see Chapters 4 and 7 for further details). Data for 2012 to 2013 indicates that 177,389 adults in England aged 18+ were deemed eligible for annual health checks.⁴ This is equivalent to 0.42% of the estimated adult population of England in 2013. These are, however, poor estimates of the actual number of adults with learning disabilities in England.

First, people may use services intermittently. That is, they may be known to councils with social services responsibilities as people with learning disabilities, but may not have been receiving a service during the year in question. Data from GP practice-based registers, for example, identified 206,132 adults with learning disabilities in the period 2012 to 2013 (see Section 4). Data from DWP indicates that 429,530 adults with learning disabilities were eligible to receive either Disability Living Allowance or Attendance Allowance (see Section 11).

Second, it is clear that the majority of adults with learning disabilities simply do not use learning disabilities services. For example, the administrative prevalence of learning disabilities (that is, the number of people known to services as people with learning disabilities) drops precipitously from approximately 3% among children in the education system (see above), to approximately 0.6% among adults aged 20 to 29.⁵ It is highly implausible that such reductions in prevalence can be accounted for by either reduced life expectancy or sudden improvements in intellectual functioning. Rather, it is likely that they reflect the impact of a combination of factors which include:

- a decrease in health/disability 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 disabilities leading to an unwillingness for people with learning disabilities to use specialised services or self-identify as having learning disabilities
- the less visible disabling impact of the intellectual impairments associated with learning disabilities in non-educational settings

Previous research commissioned by the Department of Health DH estimated that in 2004, 828,000 adults in England were likely to have learning disabilities.^{6,7} Applying these prevalence estimates to population predictions for 2013 suggests that 1,068,000 people in England have learning disabilities, of which 900,900 are adults. The latter is equivalent to 2.17% of the English adult population.

These estimates suggest that only 20% of adults with learning disabilities in England are users of specialised social care services for people with learning disabilities. The remaining 80% have been referred to as the 'hidden majority' of adults with learning disabilities who typically remain invisible in data collections used in this publication.

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 healthcare 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 distress.⁸

Similarly, analysis of the health of adults with learning disabilities who participated in the 2003 to 2004 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 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).⁹

3. Mortality

In the absence of national mortality review data, the most up to date we have on the mortality of people with learning disabilities is as follows:

- the CIPOLD found that men with learning disabilities died on average 13 years younger than men in the general population, women 20 years younger
- half of local partnership boards in their responses to the 2012 to 2013 self-assessment framework were able to provide data about people with learning disabilities sufficient to permit calculation of crudely standardized mortality ratios (SMRs). Data submitted suggested that on average the death rate for people with learning disabilities is a little more than twice that in the general population
- the median age at death of people identifiable as having learning disabilities in death certificates has risen steadily from 2008 to 2012 from 54 to 58 years

The Confidential Inquiry into premature deaths of people with learning disabilities

In March 2013 the findings of the Confidential Inquiry were published¹. This study was set up in 2010, following the recommendations of the Report of the Independent Inquiry into Healthcare for People with Learning Disabilities (the Michael Report)².

As far as possible CIPOLD studied all the deaths in a 2 year period of people known to have had learning disabilities and resident in 5 PCT areas in the South West of England, centring on the city of Bristol. Routinely recorded data such as certified causes of death were obtained. In addition to this the Inquiry undertook detailed investigations of all these deaths, contacting all relevant informants from health and social care services, family carers and any other relevant sources. A sample of deaths of people without learning disabilities was studied, using the same methods, for comparison. All available evidence was discussed by a multidisciplinary overview panel which attempted to establish whether the 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 identified and studied 249 deaths of people with learning disabilities and 58 comparators. They found that the median age at death (the age by which half of the people with learning disabilities studied had died) was 65 for men and 63 for women. This is 13 years younger than the national figure for the general population for men, and 20 years younger for women. The authors reported that 22% of people with learning disabilities were under the age of 50 at death, compared with 9% for the general population. The median age at death varied according to the level of

learning disabilities, being 67.5 for mild, 64 for moderate, 59 for severe and 46 for profound disability.

The most common certified underlying causes of death were heart and circulatory disorders (22%) and cancer (20%); these are also the two most common causes in the general population where they account for 29% and 30% of deaths respectively. 37% of deaths were at ages and from causes categorised by the methods adopted by the Office for National Statistics as likely to be amenable to prompt and good quality healthcare³.

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

National data about mortality in people with learning disabilities

The Confidential Inquiry provided very high quality data about the deaths of people with learning disabilities in the area studied in a specific 2 year period. National health surveillance to satisfy the requirements of responsibilities under Equality legislation, however, requires a process that will provide data about all parts of England on a continuous basis. At present no satisfactory system is available to do this.

There are 2 difficulties. The first is that while all people with learning disabilities dying can be assumed to have their deaths certified, death certificates do not formally identify them. Doctors can, if they think it relevant, record learning disabilities on a death certificate as a direct or contributory causes of death, however unless they think the learning disabilities had a specific relevance to the circumstances leading to the death they are not asked to do so. The Confidential Inquiry found that learning disabilities were recorded on only 23% of their subjects' death certificates.

The second difficulty is that proper analysis of numbers of deaths also requires knowledge of the numbers in the population in which the deaths occurred to calculate death rates. All this data needs to be subdivided by age and sex to allow adjustment for the different age structure of the population of people with learning disabilities (which is in part a consequence of the extent of early death). At present while we get annual counts of the total numbers of people with learning disabilities known to GPs or local authorities, these have no age/sex breakdown.

The Learning Disabilities Observatory has been working for over 2 years with the Health and Social Care Information Centre to try and remedy these gaps in the information needed to properly monitor mortality in people with learning disabilities.

What currently available data tells us

In the absence of properly comprehensive recording of learning disabilities on death certificates there are still sources that can be tapped. We have used 2 – the Self-Assessment Framework and limited analyses of death certificate data.

Self-assessment framework

The annual joint health and social care learning disabilities self-assessment exercise collects both quality ratings and statistical information about many aspects of care and support. In 2013, for the first time, local respondents were asked to say how many people with learning disabilities lived in their area giving at least a simple breakdown by age, and how many deaths had occurred in the previous year in this population, also by age group. The source from which they were advised they could get this data was GP records.

Seventy eight (out of a possible 154) Learning Disabilities Partnership Board areas (51%) were able to provide data. More details of the analysis are reported in the self-assessment numbers report⁴. We presented this data by calculating Standardised Mortality Ratios (SMRs) for each area supplying data. This measure compares the number of deaths seen in people with learning disabilities to the number expected if the age and sex specific death rates for them had been the same as in the general population of their area. Expressed as a percentage, 100% would mean there was no difference.

Local SMRs for people with learning disabilities showed such a wide range that it is unlikely that those at the top and bottom were reporting reliable figures. SMR for the area in the middle of the distribution was 220%, and the range spanned by the half of those areas above the middle and half of those below (in other words the middle half) was from 110% to 280%. We are not presenting these figures in any more detail as it is likely that their accuracy could be improved. The same questions will be asked in the Self-Assessment this year so more accurate figures may be available for our next report.

Analyses of death certificates

The difficulty of using death certificate data for studying the mortality of people with learning disabilities are described on the previous page, however it is still possible to undertake limited analyses. This is done by using the death certificates in which learning disabilities have been recorded – probably slightly fewer than a quarter of those people with learning disabilities known to their GPs. We produced a detailed report on the types of information this source shows in a special report in 2010⁵. We have not repeated these analyses since the quality of the data source is not adequate to explore for detailed trends, however previous editions of 'People with Learning Disabilities in England' have shown trends in the age at which those people with learning disabilities who can be identified have died. The most recent year for which data are available is 2012⁶.

People with learning disabilities were identified for this purpose by searching for death certificates which either specifically stated the person had learning disabilities, or else reported a condition, such as Down’s syndrome, where this can be assumed to be the case. This method is unsatisfactory since 2 of the other commonest causes of learning disabilities (cerebral palsy and hydrocephalus) cannot be included on this basis as fewer than half of those with these conditions have learning disabilities.

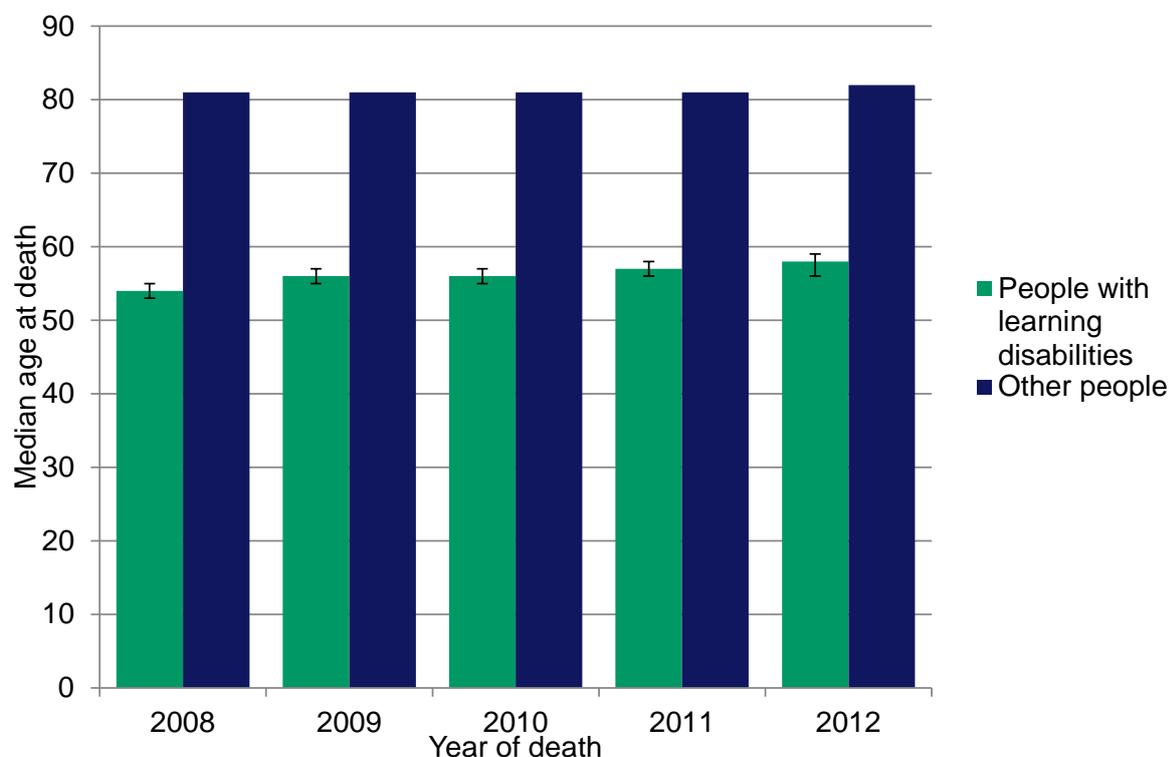


Figure 3.1. Median age at death in England for those with and without learning disabilities for each year from 2008 to 2012

Figure 3.1 shows that the median age at death for this group of people has continued to increase. In 2012 this was 58, a rise of four years since 2008. Figure 3.2 shows the profile of ages at death in more detail for people with and without learning disabilities. Bars are shown for 5 year age bands up to 95 and over. Heights of the bars represent the percentage of deaths of people with (blue) or without (red) learning disabilities occurring at that age. In each case the darker bars are the more recent years.

For people without learning disabilities, there is a small peak at the youngest age band, representing fewer than 1% of deaths. This is children who die at birth or in infancy. After this the proportion of deaths is very low until middle age, rising until the ninth decade of life. Generally the proportions of deaths have fallen in the younger age groups and risen in the two oldest.

For people with learning disabilities, the proportion of deaths peaks between the mid-fifties and mid-sixties. Trends at different age groups are less consistent, though generally higher proportions of deaths are seen at older ages.

People with Learning Disabilities in England 2013

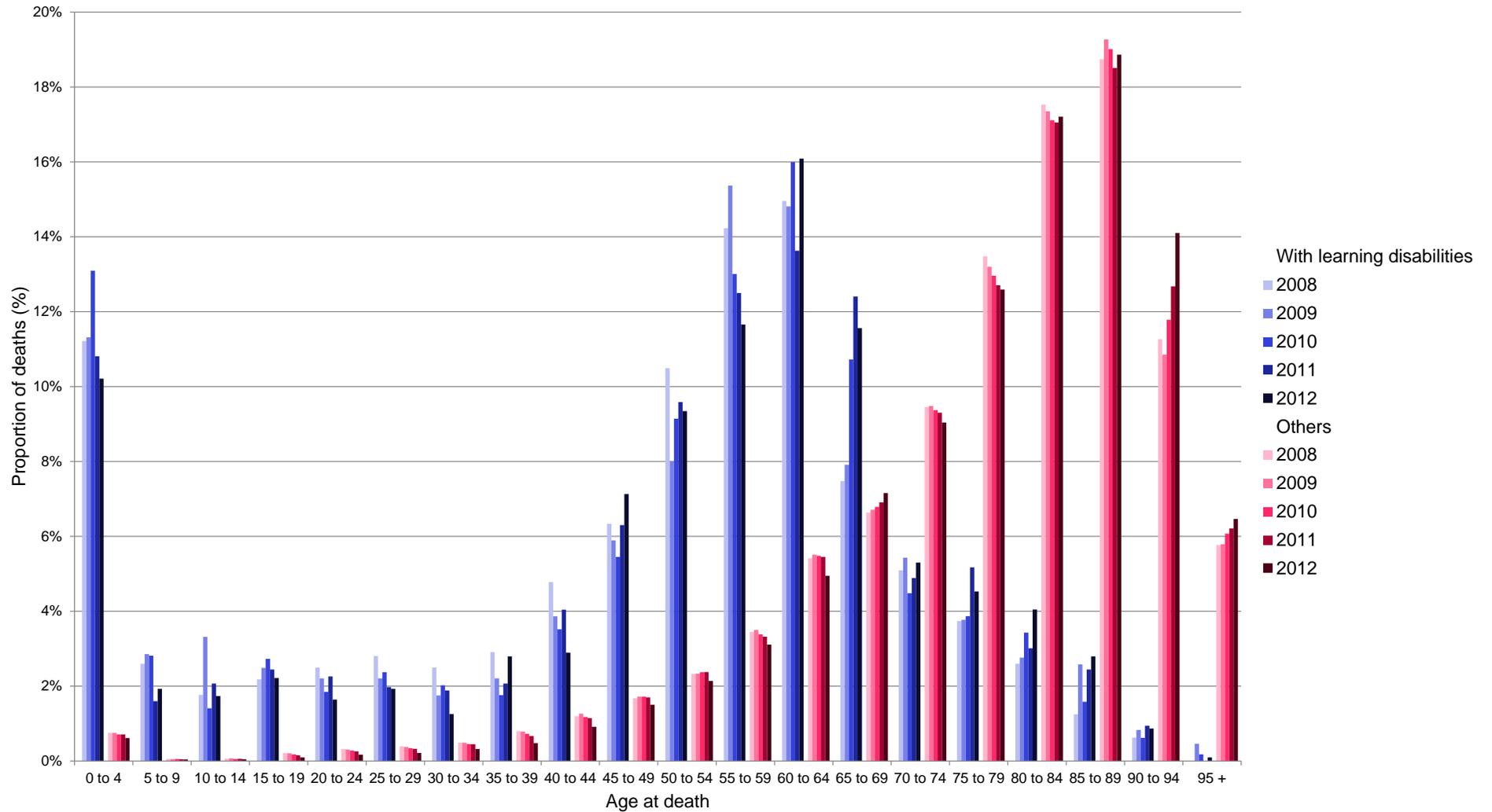


Figure 3.1. Annual proportion of deaths occurring in 5 year age bands for people with learning disabilities compared with others, 2008 to 2012

4. Health services

Summary

Information collected by the Information Centre for Health and Social Care on health services utilised by people with learning disabilities indicates that:

- GPs are recognising more people with learning disabilities on their practice lists, 4.5 in every thousand in 2011 to 2012
- marked progress has been made from financial year 2008 to 2009 to financial year 2011 to 2012 in the delivery of health checks to people with learning disabilities, with just over half (53%) of eligible adults receiving a health check in 2011 to 2012
- in 2011 to 2012, there were 104,709 attended outpatient appointments with clinical specialists who have a primary expertise in learning disabilities, up from 83,719 in 2010 to 2011

Introduction

This chapter summarises information that has been collected in relation to the use of health services by people with learning disabilities. In each of these sections, we outline why the information is important and present data by Government Office Region or NHS England area team. reports can be obtained for individual areas of local authorities that run adult social services by visiting www.ihal.org.uk/profiles and selecting the area that you are interested in. These 'learning disabilities profiles' allow you to see how each area compares with others in England.

GP register data

As part of their contract, GPs receive bonus payments for some aspects of good practice. The measurements used for deciding whether their practice is good enough to qualify for these bonuses provide valuable information about how many people have some types of health problems and the success GPs are having in managing them. This mechanism is called the Quality and Outcomes Framework (QOF).

One QOF target is that GPs are asked to keep registers of adults (aged 18 and over) on their list who they know to have learning disabilities. Each year, the Health and Social Care information Centre collects and publishes the number of people on these registers¹.

¹ Health and Social Care Information Centre. Quality and Outcomes Framework 2012 to 2013. (2013). at www.hscic.gov.uk/catalogue/PUB12262

Table 4.1 shows the numbers registered, taking the whole of England together, each year from financial year 2006 to financial year 2007 to 2012 to 2013. The table also shows these figures as rates per 1,000 adults aged 18 and over. Rate figures are not shown for the first 2 years of this programme as no comparable figures were published. Figure 4.1 shows these numbers as a graph.

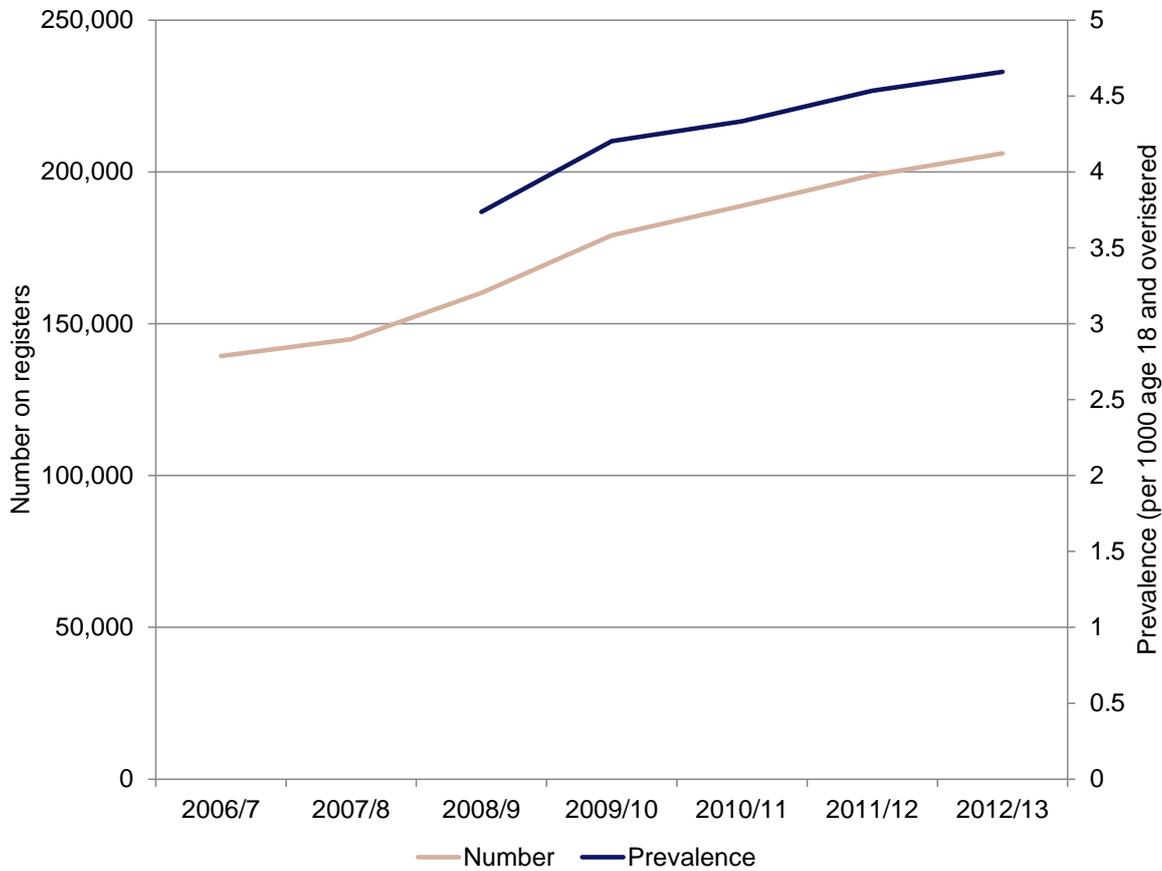
The numbers show rapid growth up to 2009 to 2010, presumably as GPs became aware of the requirement and progressively registered relevant individuals on their list. In the last 3 years the rate of growth has reduced, but a pattern of steady growth appears to have become established. It is worth noting that these figures are still much lower than those seen for numbers of children in schools with moderate or more severe 'learning difficulties' as a special educational need (see Section 5).

Table 4.1. Numbers of people on GP learning disabilities registers, percentage annual change and rates per 1000 people aged 18 and over, England, 2006 to 2007 to 2012 to 2013

Year	Number	Percentage Change in number	Rate
2006 to 2007	139,321		-
2007 to 2008	144,909	+3.9%	-
2008 to 2009	160,165	+9.5%	3.7
2009 to 2010	179,064	+10.6%	4.2
2010 to 2011	188,819	+5.2%	4.3
2011 to 2012	198,877	+5.1%	4.5
2012 to 2013	206,132	+3.5%	4.7

At present we do not know why the number of people known to have learning disabilities is rising. The data available to us is too sketchy to clarify this. It may reflect a real increase in the number of adults with learning disabilities or an increasing awareness of them by GPs.

Figure 4.2. Numbers of people on GP learning disabilities registers and rates per 1000 people aged 18 and over, England, 2006 to 2007 to 2012 to 2013



Registered rates of learning disabilities vary considerably around the country. Figure 4.2 shows the rates for each of the NHS England area teams. These range from 5.9 (95% C.I. 5.8 to 6.1) in Durham, Darlington and Tees to 3.4 (3.3 to 3.5) in London. London and the Thames Valley stand out as having substantially lower than average rates whilst 7 areas stand out at the top of the range.

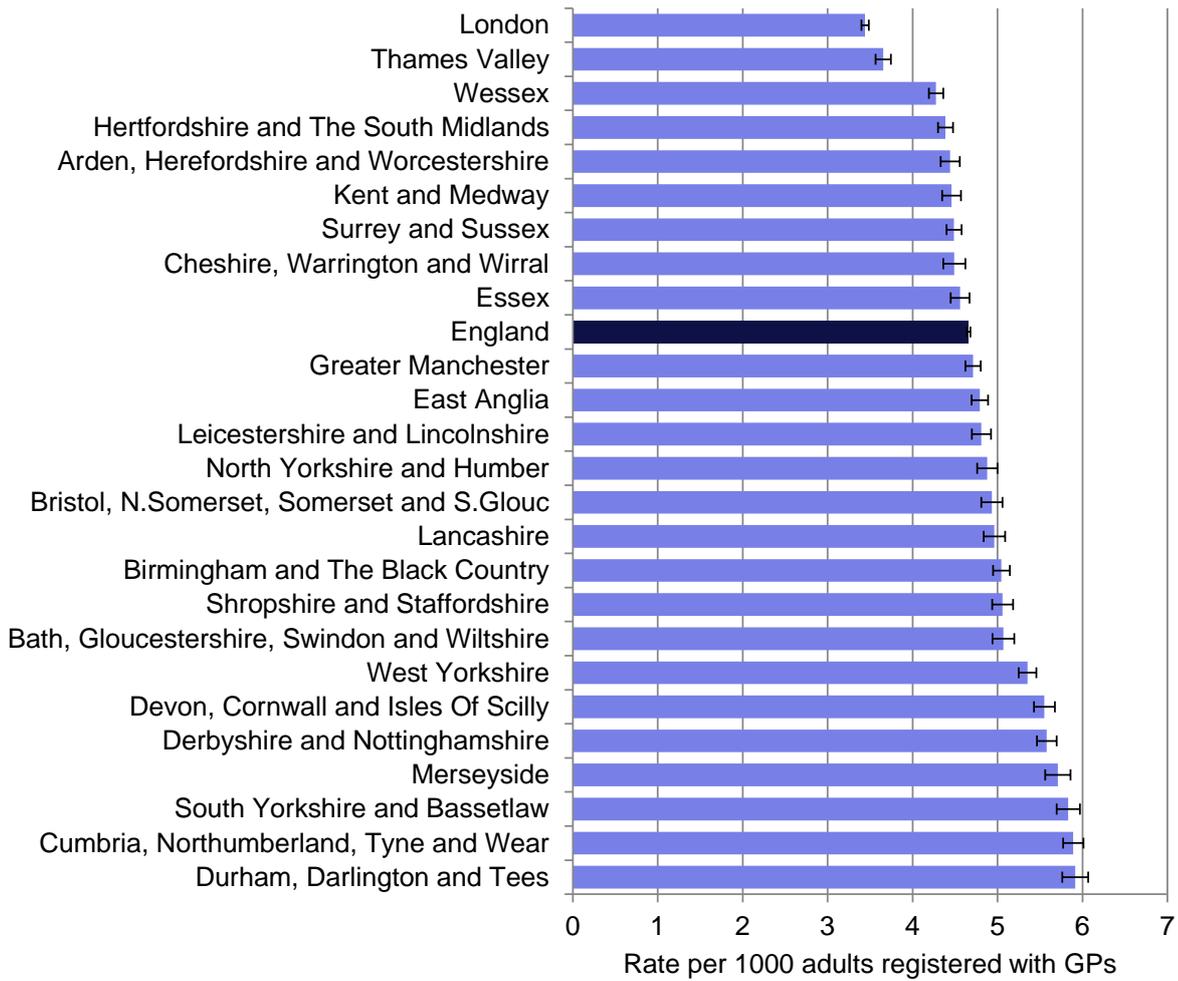


Figure 4.3. Rates of learning disabilities known to GPs per 1000 registered patients, NHS England Area Teams, England 2012 to 2013

Health Checks

People with learning disabilities have more difficulty than others in recognising ordinary health problems and getting treatment for them. Routine annual learning disabilities health checks are a standard reasonable adjustment in the delivery of primary healthcare to make this easier. In England in 2013 GPs were invited, as a Directed Enhanced Service, to provide learning disabilities health checks annually to all eligible adults aged 18 and over. Eligibility required the person to be known to have learning disabilities by both their GP and their local authority social services department. From its start in April 2008 to the end of March 2013, this scheme was administered and monitored by PCTs. Each year they reported numbers of people eligible and numbers having checks to the Health and Social Care Information Centre.

Table 4.2 summarises progress over the first 5 years of this programme.² The number of people having a learning disabilities health check rose each year, though by diminishing amounts. The number of people reported as eligible also rose each year. This number has been consistently lower than the number of people known to GPs as having learning disabilities (reported in the previous section). In 2012 to 2013 it was 82% of the number known to GPs. In part this is because not all people known to GPs as having learning disabilities are known to their local authority, however, it also appears that in some areas, potentially eligible people registered with GP practices that chose not to participate in the scheme were not reported.

The number having checks rose faster than the number reported as eligible in each year up to 2011 to 2012, hence the coverage (number of checks as a proportion of number eligible) also rose each year. In 2011 to 2012 for the first time this measure exceeded 50%, however in 2012 to 2013, the number of people reported as eligible rose faster than the number of people having checks. As a result the coverage figure fell slightly from 53% to 52%.

Table 4.2: uptake of Annual Health Checks for People with Learning Disabilities 2008 to 2009 to 2011 to 2012 (& percentage change from previous year)

	2008 to 2009	2009 to 2010	2010 to 2011 (revised)	2011 to 2012 (revised)	2012 to 2013
Number of people who received a health check	27,011	58,919 (+118%)	73,068 (+24%)	86,134 (+18%)	92,329 (+7%)
Number of people identified as eligible to receive a health check	118,230	145,130 (+23%)	153,021 (+5%)	162,991 (+7%)	177,389 (+9%)
% of identified eligible people who received a health check	23%	41% (+78%)	48% (+18%)	53% (+11%)	52% (-1%)

The proportion of eligible people reported to have received a health check varied between areas. Figure 4.3 below shows the variation between Strategic Health Authority areas over the first 5 years of the programme. All showed increases in coverage each year up to 2011 to 2012, however in 2012 to 2013, half showed falls.

² In 2011 to 2012 and 2012 to 2013 a number of PCTs requested an opportunity to revise the figures submitted the previous year. This was agreed and small numbers did so. Figures shown are the revised ones. In practice this made very little overall difference.

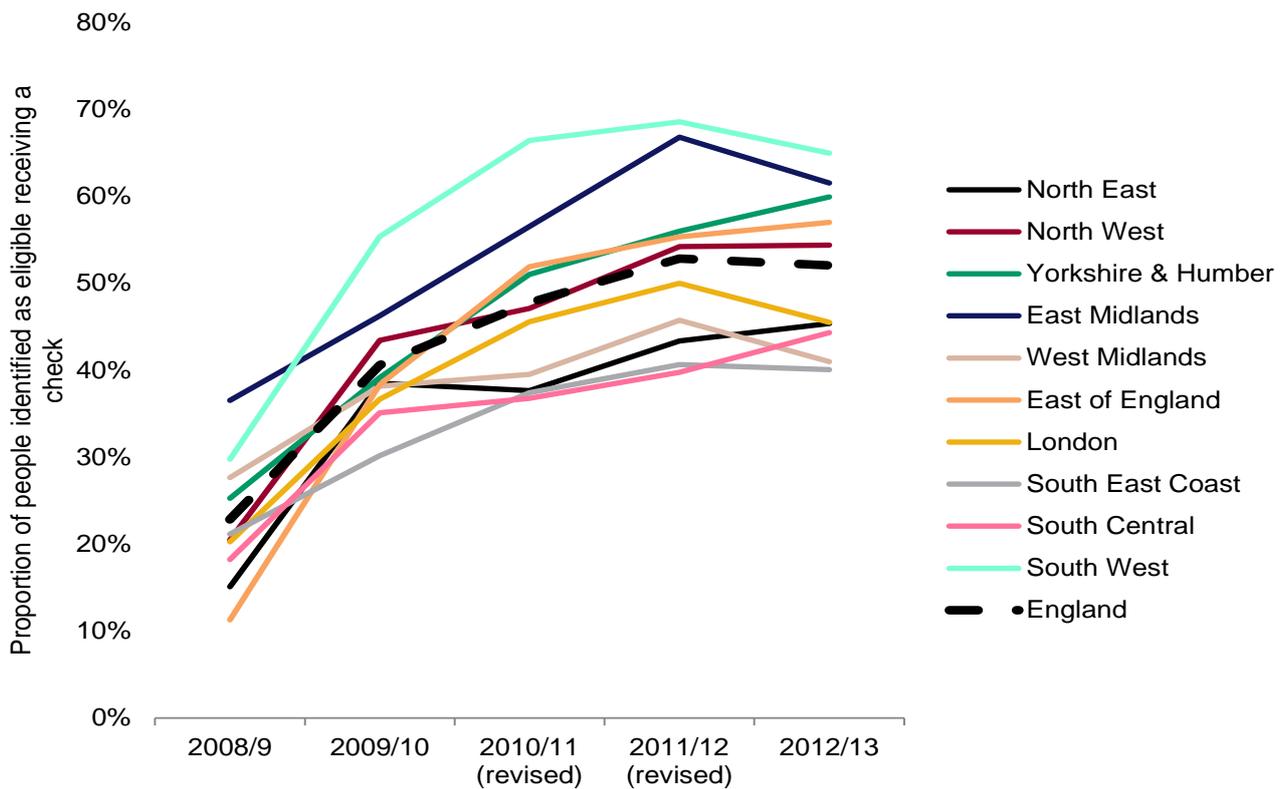


Figure 4.3: Proportion (%) of eligible adults with learning disabilities receiving a health check from their GP by Strategic Health Authority, 2008 to 2009 to 2012 to 2013.

The variation in reported performance at PCT level was much greater and has been throughout the four years. In 2012 to 2013 the bottom 10% of PCTs provided health checks for fewer than 30% of eligible adults whilst the best 10% exceeded 75%. In the previous four years these markers have improved in each year with the bottom 10% achieving 0%, 14%, 24%, and 28% while the top 10% achieved 55%, 67%, 70% and 73%. Map 4.1 shows the coverage rates in 2012 to 2013 at PCT level, however all these figures are open to the question of how completely patients with learning disabilities registered with practices not participating in the health check scheme were reported as eligible. In England the number of people having health checks was 52% of the number reported as eligible, but only 44% of the number reported as known to GPs on learning disabilities registers. Changes in reporting suggest that from 2013 to 2014 we are likely to be reporting coverage in relation to numbers on GP learning disabilities registers. This is likely to give a more consistently reliable picture of activity across the country, however, it is also likely to show some sharp changes in apparent coverage in some CCG areas.

Map 4.1 shows the percentage of adults reported as eligible who received an annual learning disabilities health check for PCTs in England during 2012 to 2013.



Hospital care for people with learning disabilities

A set of official government statistics called Hospital Episode Statistics records the use of hospital care provided or funded by the NHS. Hospital Episode Statistics cover all clinical disciplines and record numbers of admissions, outpatient attendances and attendances at accident and emergency departments. Unfortunately it is not possible at present to satisfactorily identify patients who have learning disabilities among those admitted to general hospitals or attending outpatient clinics or A&E departments for treatment of physical illnesses. This is because while age, sex, ethnic group, place of residence and registered general practitioner are recorded for everyone, disabilities are not. Diagnoses are recorded for admissions, and both a primary and multiple secondary diagnoses are accommodated. Learning disabilities are sometimes reported as a secondary diagnosis when people are admitted to hospital for other conditions. However our own (unpublished) studies show that this is erratic; where individuals are reported to have learning disabilities at one admission this is frequently not reported at others.

The most satisfactory solution to obtaining data about hospital care for this group would be to take learning disabilities register details from general practices throughout the country and to link these nationally, in the secure data linkage facilities of the Health and Social Care Information Centre, to data about all types of hospital usage. This would permit analysis of patterns of hospital usage and the success of hospital care to be reported. Linking these registers to national cancer and diabetes registers would permit similarly comprehensive analysis of how frequently these conditions are found in people with learning disabilities, the stages at which they are diagnosed, the treatments that are offered and the success achieved in managing them. This is a clearly achievable approach which would not require the collection of any new data. All it would require would be more effective management of data already held in various parts. The Observatory has been pressing for this for some time.

The one area of the care of people with learning disabilities which can be clearly seen in inpatient and outpatient statistics is mental healthcare. This is because there is a sub-specialty in psychiatry concerned specifically with people with learning disabilities. Activity under this group of doctors can be reasonably assumed to relate to people with learning disabilities, however how comprehensive a picture this gives we do not know because some people with learning disabilities may be under general psychiatrists or psychiatrists with other specialist roles, such as child psychiatry, forensic psychiatry or psychiatry of old age.

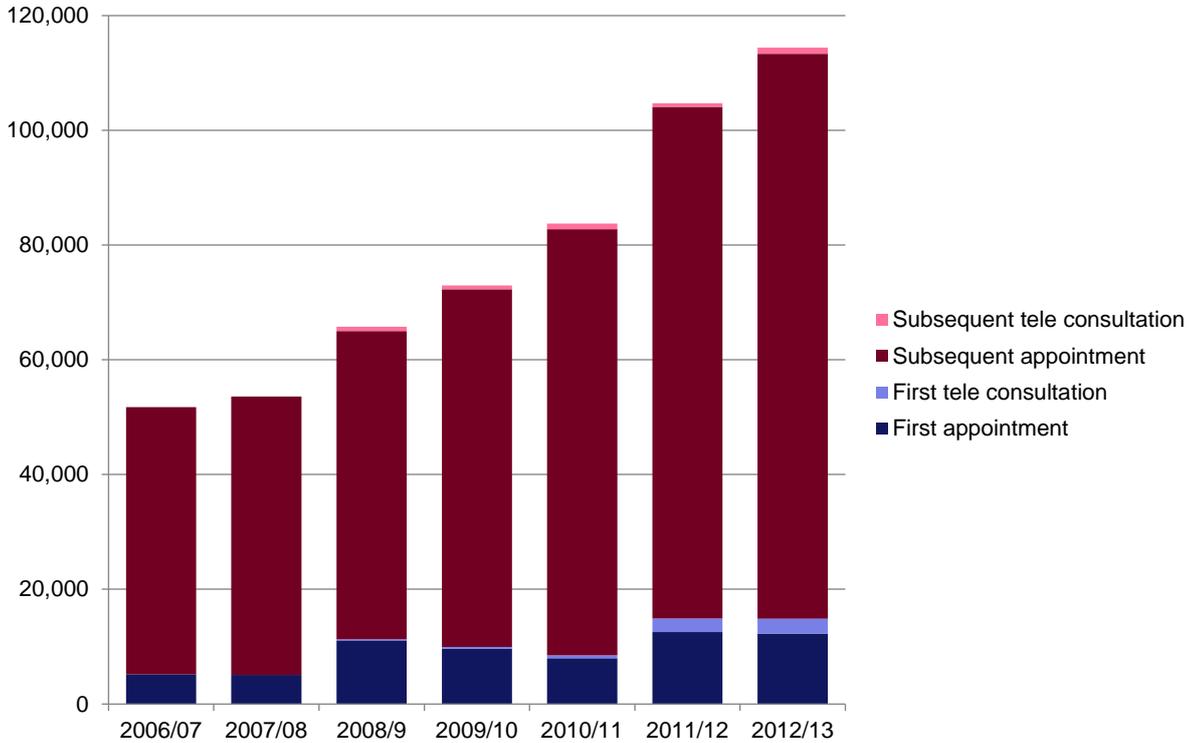
Outpatient mental healthcare

Published statistics of outpatient care report numbers of attendances at outpatient clinics in the specialty of psychiatry of learning disabilities (see Figure 4.4). These are further divided into first and subsequent attendances. This is a relatively new collection; published statistics start from 2006 to 2007 and the format slightly altered in 2008 to 2009 to allow separate reporting of telephone consultations.³ The data shows overall numbers of attendances climbing steadily. The number of first attendances has been stable or falling in most of the last 5 years, although

³ This information has been extracted from data tables available at:
<http://www.hscic.gov.uk/searchcatalogue?productid=10254&q=outpatient&topics=0%2fHospital+care&sort=Title&size=10&page=3#top>

with a step up between 2010 to 2011 and 2011 to 2012. The responsible senior statistician at the Health and Social Care Information Centre advised us that there have been no changes in scope or definitions likely to call into question the comparability of these figures since 2008 to 2009.

Figure 4.4. Number of hospital outpatient clinic attendances in the speciality of psychiatry of learning disabilities



Inpatient mental healthcare

Hospital episode statistics in mental healthcare describe the numbers of admissions to NHS psychiatric hospitals. As for outpatient contacts, people with a learning disabilities can largely be identified by the speciality of the consultant under whom they are admitted, psychiatry of learning disabilities/disability?.

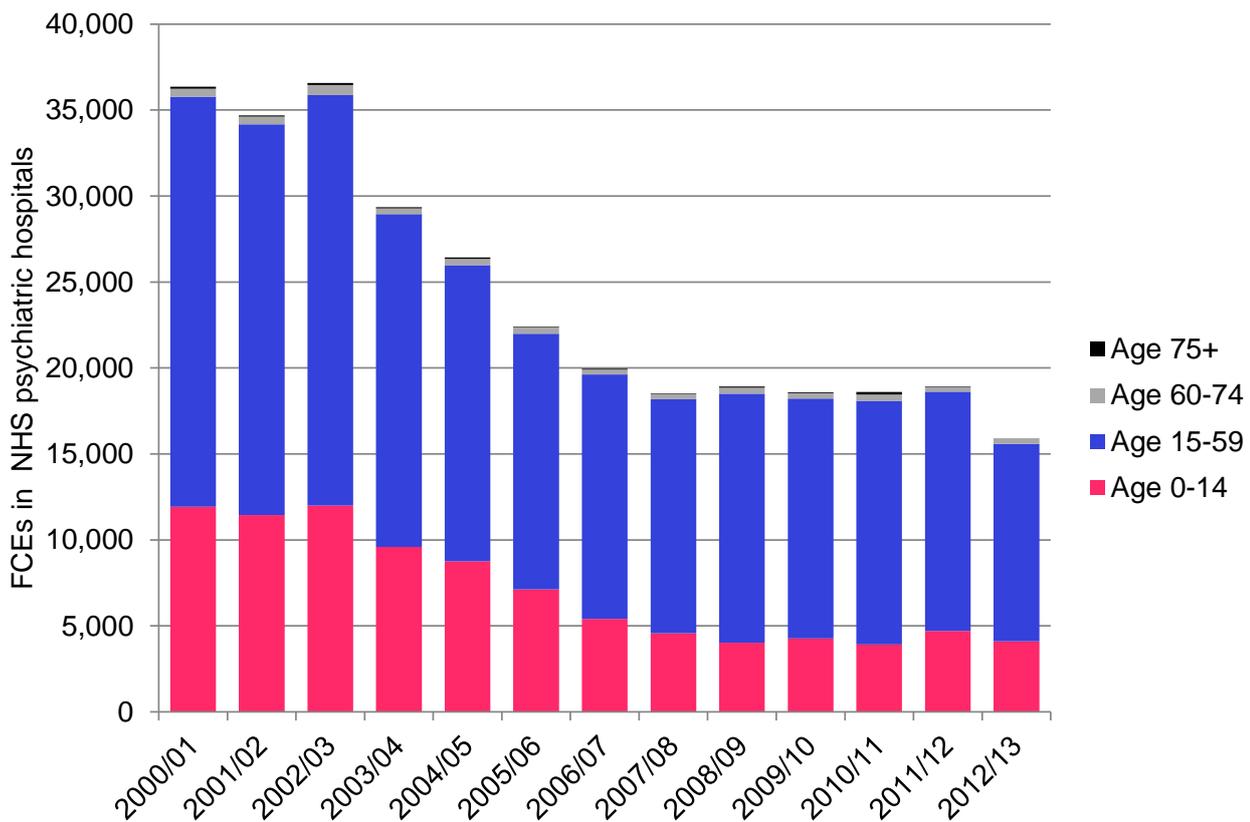


Figure 4.5: inpatient finished consultant episodes (FCEs) in NHS hospitals under the specialty of psychiatry of learning disabilities

Figure 4.5 shows the numbers of ‘finished consultant episodes’ in this specialty in each of the years from financial year 2000 to 2001 to financial year 2012 to 2013, the most recent currently published. A ‘finished consultant episode’ is a period of time in hospital under the care of a consultant in a particular specialty or subspecialty. This is broadly similar to an admission and in most cases amounts to the same thing. It differs where during the course of an admission a person’s care is passed from one consultant to another for the purpose of obtaining a different sort of specialist care.

The published data shown in Figure 4.5 does not include admissions to independent sector hospitals. In psychiatric services these provide a substantial proportion of NHS funded low and medium secure inpatient care, however in most cases they do not submit standard NHS statistical returns to the Health and Social Care Information Centre for the psychiatric work the NHS pays them to do. This omission is difficult to understand since it means that published official statistics in this area are in this way incomplete.⁴

Figure 4.5 is remarkable in several ways. First there is a sharp declining trend seen from financial year 2003 to 2004 to financial year 2007 to 2008. This closely resembles the trend in psychiatric admissions generally, although the fall is greater. Other psychiatric admissions fall by 25% over this period; admissions for psychiatry of learning disabilities fell by roughly 50%.

⁴ Independent sector mental hospitals differ in this from independent hospitals undertaking surgical and other care under NHS funding which make returns to Hospital Episode Statistics in the ordinary way

Second, in comparison to general psychiatric admissions the age profile is very different. 66% of the admissions in 2001 to 2002 were of people aged 15 to 59. This rose to roughly 75% in 2006 to 2007. At the start of the decade around a third of the admissions were of children. This fell to around a quarter. Admissions of older people made up around 2%. By comparison, in other types of mental healthcare, admissions of people aged 15 to 59 made up roughly the same fraction, but admissions of children were rare – usually less than 1% of the total - and admissions of people aged 60 or older made up the remainder.

Third, the overall number of admissions is remarkably high. The next section gives outline details of the findings of a census of people with learning disabilities or autism in psychiatric inpatient care in England in 2013. That identified 1,804 people in NHS beds, however half of these had been in hospital longer than a year, and three quarters for more than 3 months. Only 457 had been in less time than this. This suggests a remarkably fast turnover in a very small number of beds in the context of the very slow moving picture in the majority of beds described in more detail below. Published hospital episode statistics show a median stay length (the time by which half of those admitted have been discharged) of three days. This is remarkably consistent over time, not changing through the whole decade and suggests that a large proportion of the admissions being counted are for respite.

The learning disabilities psychiatric inpatient census

Following the publication of the government's report 'Transforming Care: a National Response to Winterbourne View Hospital', a national census was conducted of people with learning disabilities or autism in psychiatric inpatient care covering NHS and independent psychiatric hospitals. The policy aim set out in the introduction to the document was to reduce or eliminate lengthy inpatient stays for people who could be better supported in non-hospital settings. The census was intended to identify the number of people involved, where they were and the types of service they were receiving. A further census was planned for a year later. The format of the census and the data collections closely followed the Count-Me-In censuses done annually from 2006 to 2010 except that only people with learning disabilities or autism were included.

Overall 3,250 people with learning disabilities or autism and normally resident in England were in hospital on the census day (30 September 2013). This was a reduction of 35% on the 5,001 people in the 2010 census meeting a comparable definition. The reduction in specialist learning disabilities beds was 27%. A much greater drop (60%) was seen for the minority in beds not specifically designated for people with learning disabilities, raising the possibility that these might have been less effectively identified in the 2013 census. The number of NHS beds had reduced by 47%, that of independent sector beds by only 11%.

Three quarters of current in-patients were male, 49% aged 18 to 34 and 6% aged under 18. 76% were in beds specifically provided for people with learning disabilities as opposed to generic mental health facilities. 27% had been in hospital less than 6 months, 31% between 6 months and 2 years and 42% longer. 18% had been in hospital longer than 5 years and 6% - 198 patients - longer than 10 years.

Thirty three percent were hospitalised within 20 kilometres of their home, but 37% were more than 50 kilometres distant.

Fifteen percent were being actively treated for mental illnesses, and 29% working towards a discharge plan. A further 46% were described as currently receiving active treatment but

without a discharge plan and just fewer than 4% were described as needing indefinite in-patient care because of their behavioural needs.

1,780 patients (55%) were in secure units of some type. Secure services are described by the NHS standard contract as being provided for 'individuals with mental disorder or neuro-developmental disorder who are liable to be detained under the Mental Health Act (1983) and whose risk of harm to others and risk of escape from hospital cannot be managed safely within other mental health settings'. 1,195 (37%) patients were in low secure accommodation, 512 (16%) in medium secure and 73 (2%) in high secure. These included 21 aged under 18 in low secure and 40 in medium secure units.

2,447 (79%) adults and 89 (55%) of those aged under 18 were detained under the 1983 Mental Health Act, 1002 (32%) adults and 15 (9%) aged under 18 were detained under powers that are exercised by criminal courts or (in relation to prisoners) by the Ministry of Justice. This means that they must have come before the courts and / or been convicted of imprisonable offences as part of the pathway leading to their placement in hospital. 20% of adults and a small number of those aged under 18 were further placed under Mental Health Act 'Restriction Orders', meaning that they could not be discharged or given leave of absence from hospital without the agreement of the Ministry of Justice. This additional limitation is imposed by courts when the judge takes the view that it is necessary in order to protect the public from a risk of serious harm.

There was surprisingly wide variation around the country in both the rates of hospitalisation and the level of legal powers that had been imposed. Figure 4.6 shows this for adult patients. The Health and Social Care Information Centre which undertook the survey checked the normal place of residence for all the patients against the NHS central register. Numbers hospitalised under various legal powers per 1,000 people with learning disabilities known to GPs are shown for standard Government Office Regions. Across England 13 adults were in hospital per 1,000 adults with learning disabilities known to their GP. The figure for the South West was under half of this (45%), and that for the North East was almost double (181%).

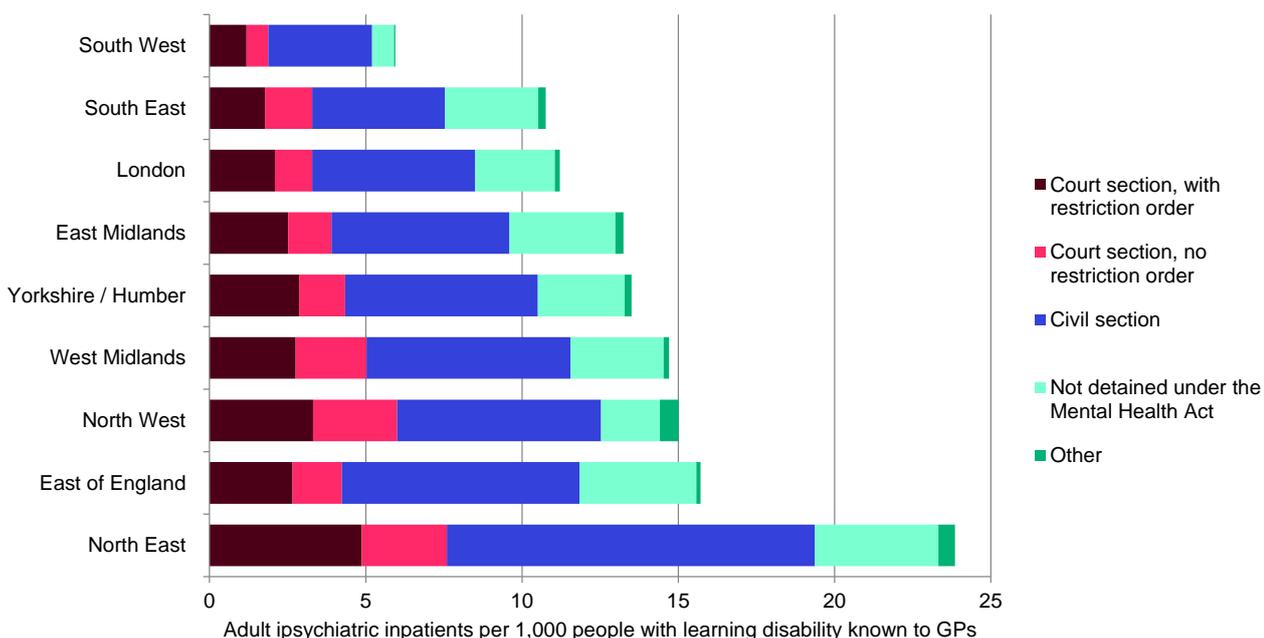


Figure 4.6 Prevalence of inpatient care for adults with learning disabilities by region of residence and legal status on census day.

It might be supposed that this meant that in the North East people were being admitted for less severe problems and so a higher proportion would be informal. In fact the number detained both under civil sections (imposed by doctors and social workers) and under restriction orders, the most severe type of court provision, were both almost double that in other areas in relation to the size of the population with learning disabilities. These and many other findings from the census have important implications for the process of trying to reduce the overall number of people in hospital.

5. Education

Summary

Information collected by the DfE on the education of children with SEN associated with learning disabilities shows that:

- overall, approximately 180,000 children in England were identified in 2012 to 2013 as having a primary SEN associated with learning disabilities. Of these, nearly 4 out of 5 had a MLD, 1 in 6 had severe learning difficulties (SLD) and 1 in 20 had profound multiple learning difficulties (PMLD). An additional 46,000 children were identified as having a secondary SEN associated with learning disabilities
- over 70,000 children in England have a Statement of SEN and a primary SEN associated with learning disabilities. Of these, just under half had MLD, over one third had SLD and 1 in 8 had PMLD
- between 2009 to 2010 and 2012 to 2013, the number of children identified as having a primary SEN associated with learning disabilities reduced by 15%, even though the total number of children on school rolls increased by 2%
- SEN associated with learning disabilities is more common among boys, children from poorer families and among some minority ethnic groups
- overall, 88% of children with MLD, 22% of children with SLD and 17% of children with PMLD are educated in mainstream schools. These rates are declining among children with learning disabilities, especially children with SLD
- there was substantial variation across local authorities in the percentage of children with a primary SEN (School Action Plus or with statements) associated with learning disabilities who were placed in mainstream schools
- for children with SLD: the 10% of councils making most use of mainstream schools placed 44% or more of children in mainstream schools; the 10% of councils making least use of mainstream schools placed less than 8% of children in mainstream schools
- for children with PMLD: the 10% of councils making most use of mainstream schools placed 32% or more of children in mainstream schools; the 20 councils (13%) making least use of mainstream schools placed no children with PMLD in mainstream schools
- children with a primary SEN associated with learning disabilities were more likely than other children to be absent from school and to be excluded from school (including permanent exclusion)

Introduction

Information on the education of children with SEN associated with learning disabilities is provided in a series of annual reports published by the DfE. The SEN (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 well-being of these pupils. This requirement has led to the publication of the annual series 'Children with Special Educational Needs: An Analysis'.¹⁻⁵

The primary source of information for this reporting 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 age.⁶

Unless specified, 2012 to 2013 information contained in this section is extracted from Children with SEN 2013: An Analysis⁵ and associated statistical first releases from the DfE.^{7 8}

The identification of children with SEN associated with learning disabilities

The identification of SEN is undertaken at 3 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)

The recording of SEN at School Action level is of questionable validity. As a result, all information contained in this section relates to children with SEN associated with learning disabilities at either School Action Plus or who have a statement of SEN.

The school census records the child's primary and, if relevant, secondary type of SEN against a specified list. Three types of SEN are associated with learning disabilities: MLD, SLD and PMLD.

Table 5.1 presents data from the series 'Children with Special Educational Needs: An Analysis' on the number of children with a primary SEN associated with learning disabilities in state funded primary, secondary and special schools and non-maintained special schools in England.

Overall, approximately 180,000 children in England were identified in 2012 to 2013 as having a primary SEN associated with learning disabilities. Of these, over 3 out of 4 had MLD, 1 in 6 had SLD and 1 in 20 had PMLD.

Over 70,000 children in England have a statement of SEN and a primary SEN associated with learning disabilities. Of these, just under half had MLD, over one third had SLD and 1 in 8 had PMLD.

Between 2009 to 2010 and 2012 to 2013, the number of children identified as having a primary SEN associated with learning disabilities reduced by 15%, even though the total number of children on school rolls increased by 2%. As a result, the prevalence of Primary SEN associated with learning disabilities decreased from 2.6% in 2009 to 2010 to 2.1% in 2012 to 2013. This reduction was primarily accounted for by a reduction in the prevalence of children identified with MLD from 2.1% in 2009 to 2010 to 1.7% in 2012 to 2013. The prevalence of children identified with SLD showed a marginal decrease from 0.36% in 2009 to 2010 to 0.33% in 2012 to 2013. The prevalence of children identified with PMLD remained static at 0.12%.

Table 5.1: the number of children with a primary SEN (School Action Plus or with statements) associated with learning disabilities in state funded primary and secondary schools and state funded and non-maintained special schools in England, 2009 to 2010 to 2012 to 2013

Type of SEN	School Action Plus	% ^a	Statement	% ^a	Total	% ^a
2009 to 2010						
MLD	130,620	96.8%	41,030	54.8%	171,650	81.8%
SLD	3,620	2.7%	25,230	33.7%	28,850	13.7%
PMLD	720	0.5%	8,680	11.6%	9,400	4.5%
Total	134,960	100.0%	74,940	100.0%	209,900	100.0%
2010 to 2011						
MLD	124,105	96.9%	36,645	51.0%	160,750	80.4%
SLD	3,225	2.5%	26,045	36.3%	29,270	14.6%
PMLD	795	0.6%	9,100	12.7%	9,895	5.0%
Total	128,125	100.0%	71,790	100.0%	199,115	100.0%
2011 to 2012						
MLD	114,805	96.8%	34,715	48.9%	149,520	78.8%
SLD	3,055	2.6%	26,880	37.8%	29,935	15.8%
PMLD	795	0.7%	9,460	13.3%	10,255	5.4%
Total	118,655	100.0%	71,055	100.0%	189,710	100.0%
2012 to 2013						
MLD	104,900	96.6%	33,455	47.3%	138,355	77.2%
SLD	2,900	2.7%	27,540	38.9%	30,440	17.0%
PMLD	805	0.7%	9,715	13.7%	10,525	5.9%
Total	108,605	100.0%	70,710	100.0%	179,320	100.0%
%Change 2009 to 2010 – 2012 to 2013 (compound annual growth rate)						
MLD	-7.0%		-6.6%		-6.9%	
SLD	-7.1%		+3.0%		+1.8%	
PMLD	+3.8%		+3.8%		+3.8%	
Total	-7.0%		-1.9%		-5.1%	
^a Percentage of children with primary SEN associated with learning disabilities						

An additional 45,610 children were identified as having a secondary SEN associated with learning disabilities (School Action Plus or statement).⁸ Of these, 86% had MLD, 13% had SLD and 1% had PMLD. Of the children identified as having a secondary SEN of MLD: 32% had a

primary SEN of speech, language and communication needs; 32% behaviour, emotional and social difficulties; 18% autistic spectrum disorder; 8% physical disability; 5% some form of sensory impairment; 3% specific learning difficulty; 3% other difficulty/disability; 1% multiple sensory impairment.

Sex

SEN associated with learning disabilities is more common among boys. Table 5.2 presents data from SEN in England, January 2013⁸ on the prevalence of primary SEN associated with learning disabilities by sex.

Table 5.2: number and percentage of girls and boys with primary SEN (School Action Plus or with statements) associated with learning disabilities in January, England 2013				
	Girls with type of primary SEN		Boys with type of primary SEN	
	Number	%	Number	%
MLD	50,380	1.35%	89,975	2.26%
SLD	10,915	0.29%	19,525	0.50%
PMLD	4,615	0.12%	5,905	0.15%
Total	65,910	1.77%	113,405	2.92%

Age

The association between child age and the identification of primary SEN (School Action Plus or with statements) associated with learning disabilities is presented in Figures 5.1 and 5.2 among children aged 5 to 16 at the start of the academic year in 2013. Calculating prevalence rates for SEN associated with learning disabilities is likely to be unreliable outside the age-band where schooling is compulsory. This is because children may enrol early or stay on to later ages as a result of some types of disability, and be more likely to leave at the earliest possible date as a result of other types of disability.

Overall the identified prevalence rates of SEN of MLD and SLD increase sharply across the primary school ages and then either decline (MLD) or remain stable (SLD). For children with PMLD rates of identification are high on entry to primary school before dropping slightly but steadily at older ages. The difference in these trends is probably related to the ease of identification of profound multiple learning difficulties in young children.

Figure 5.1: age-specific prevalence per 1,000 of Primary SEN (School Action Plus or with statements) of MLD with 95% confidence intervals (Wilson method), 2013

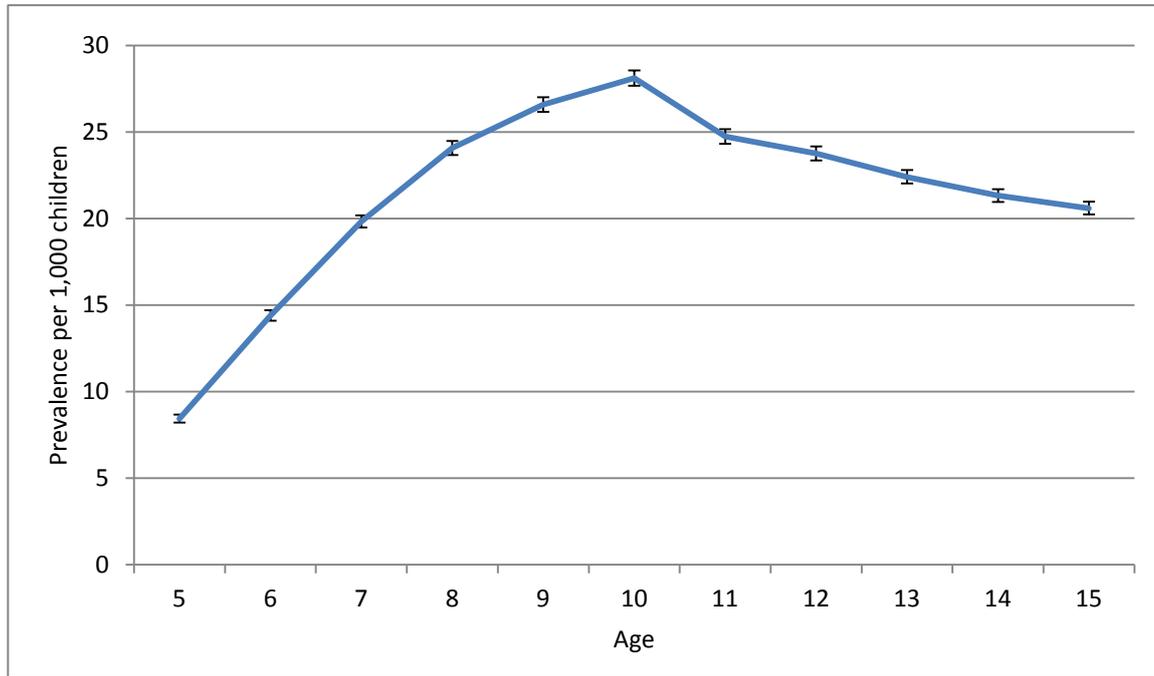
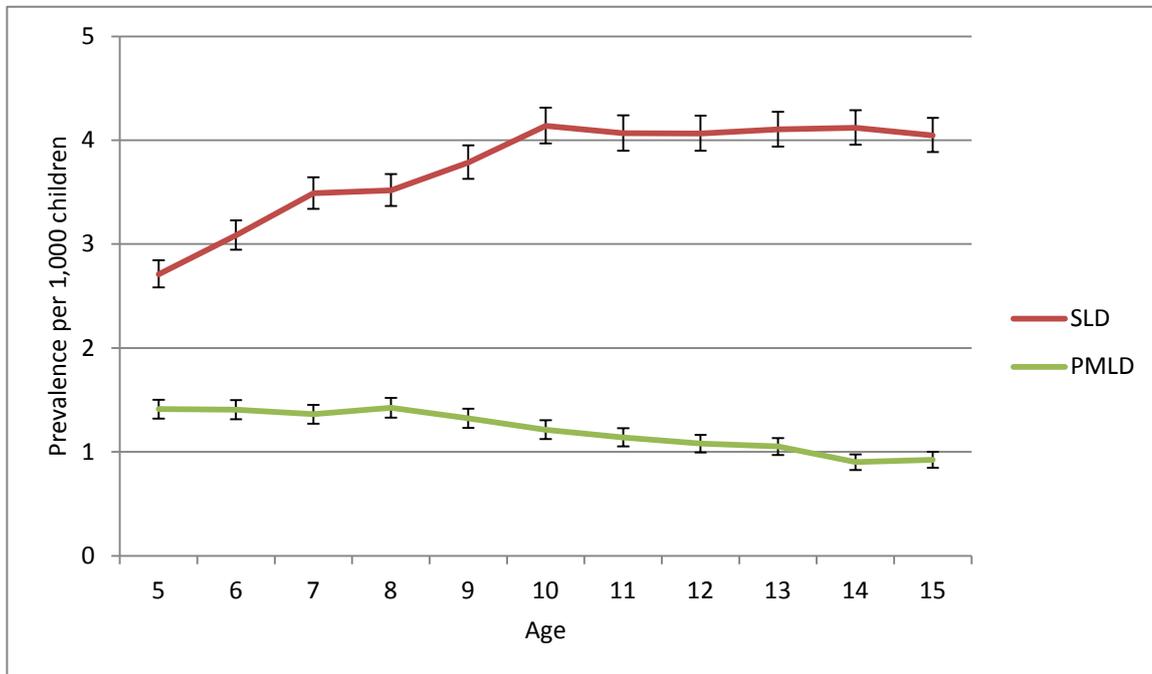


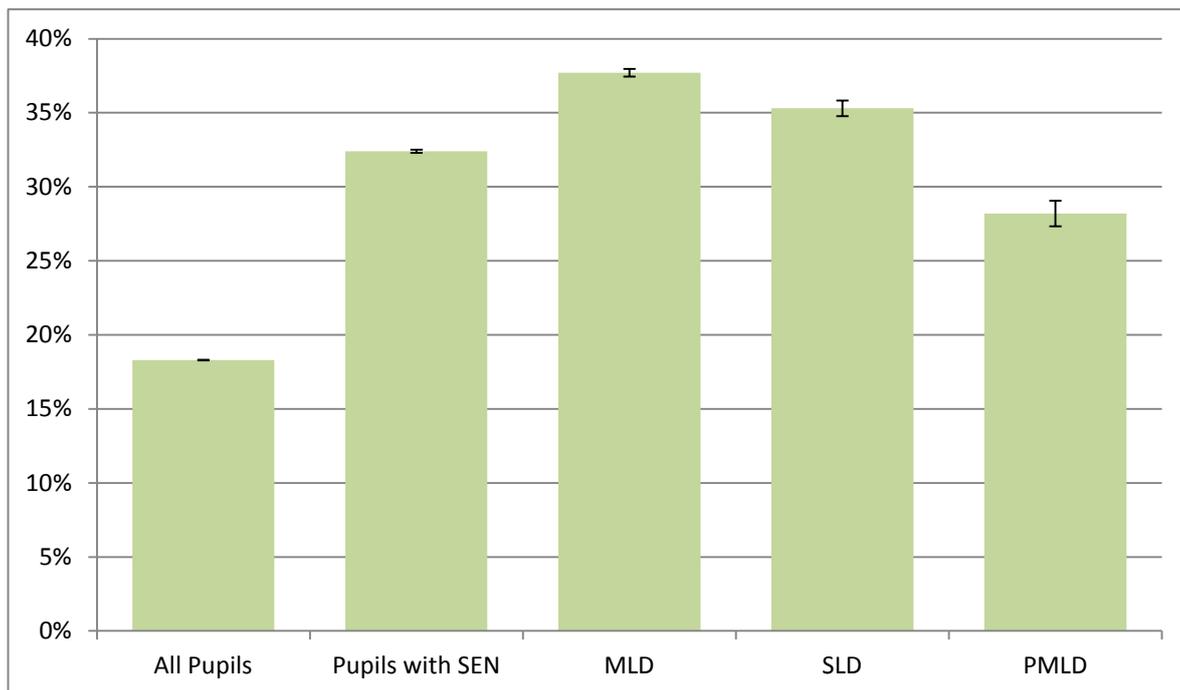
Figure 5.2: age-specific prevalence per 1,000 of primary SEN (School Action Plus or with statements) SLD and PMLD with 95% confidence intervals (Wilson method), 2013



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 disabilities.⁶ Figure 5.3 shows the percentage of children without SEN and with primary SEN (School Action Plus or with statements) associated with learning disabilities that are eligible for free school meals (that is, living in poorer households) in 2013.

Figure 5.3: percentage of children without SEN and with primary SEN (School Action Plus or with statements) associated with learning disabilities that are eligible for free school meals in 2013



Ethnicity

The identified prevalence of SEN associated with learning disabilities differs considerably between ethnic groups.⁶ Figures 5.4 to 5.6 present information on the ethnic composition of children with primary SEN (School Action Plus or with statements) associated with learning disabilities for all minority ethnic groups in 2013.

In 2013 74% of children with a primary SEN of MLD were recorded as ‘white British’ compared with 71% of children with a primary SEN of SLD and 64% of children with a primary SEN of PMLD. These differences primarily reflect the higher rates of severe and profound multiple learning difficulties among ‘Pakistani’ and ‘Bangladeshi’ children. These differences in prevalence remain apparent in analyses that control for the potentially confounding effects of differences between ethnic groups in levels of exposure to household and neighbourhood deprivation.⁶

Figure 5.4: Ethnic composition of children with primary SEN (School Action Plus or with statements) of MLD, 2013

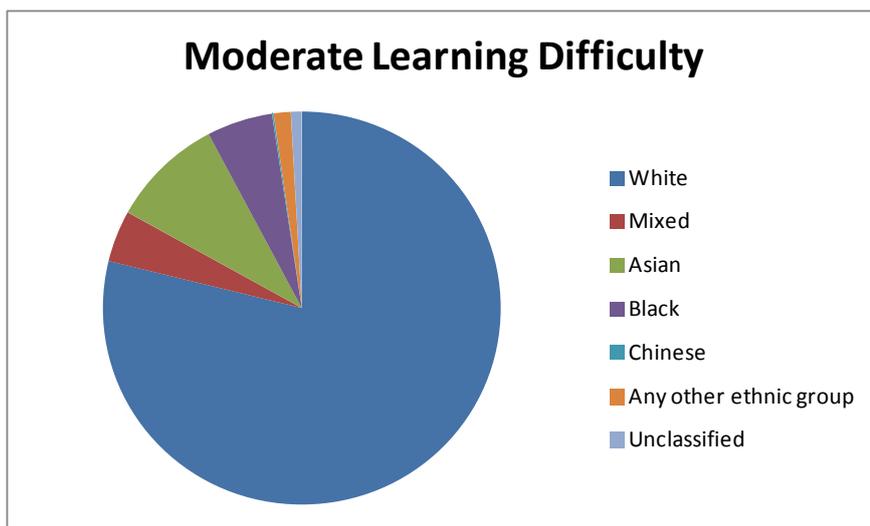


Figure 5.5: ethnic composition of children with primary SEN (School Action Plus or with statements) of SLD, 2013

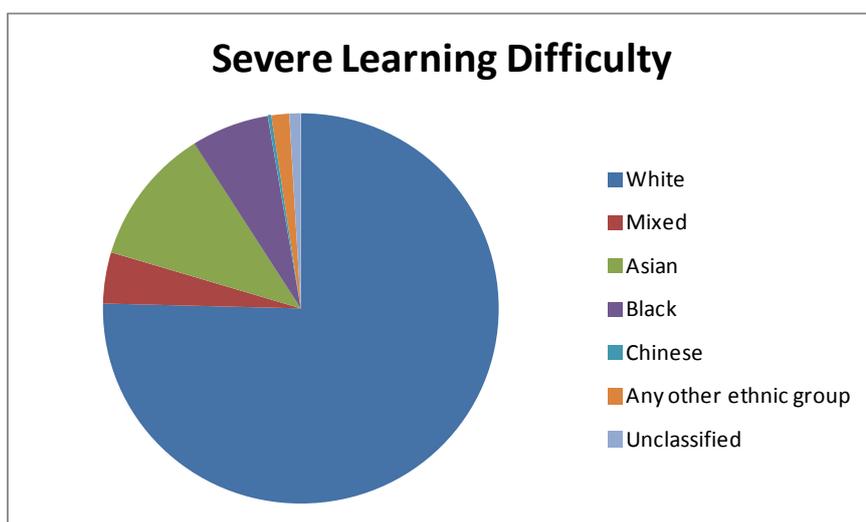
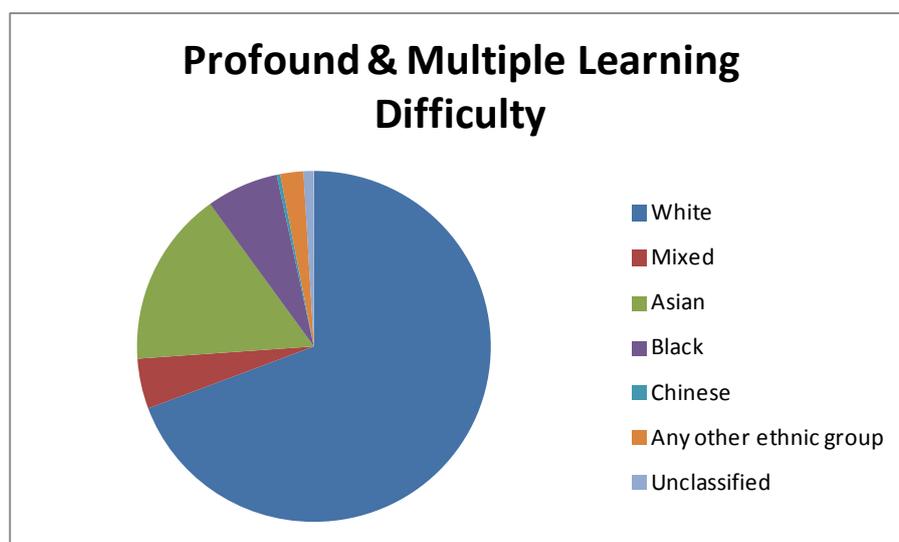


Figure 5.6: ethnic composition of children with primary SEN (School Action Plus or with statements) of PMLD, 2013



Mainstream and special schools

The ‘Children with Special Educational Needs’ series contains information on the number of children with primary SEN (School Action Plus or with statements) associated with learning disabilities who are educated in mainstream and special schools (Table 5.3).

Overall, nearly 3 out of 4 children with a primary SEN (School Action Plus or with statements) associated with learning disabilities were being educated in mainstream schools in 2012 to 2013, however, this dropped to 22% of children with a primary SEN of SLD and 17% of children with a primary SEN of PMLD.

Table 5.3: percentage of children with SEN associated with learning disabilities being educated in mainstream schools 2008 to 2009 to 2012 to 2013						
	2008 to 2009	2009 to 2010	2010 to 2011	2011 to 2012	2012 to 2013	Compound Annual Growth Rate
MLD	88.6%	88.6%	88.7%	88.3%	87.6%	-0.3%
SLD	26.8%	26.8%	24.3%	22.7%	21.7%	-5.1%
PMLD	18.3%	18.3%	18.3%	17.8%	17.4%	-1.3%
Total	76.9%	76.9%	75.8%	74.1%	72.2%	-1.6%

Between 2008 to 2009 and 2012 to 2013 the percentage of children with a primary SEN (School Action Plus or with statements) associated with learning disabilities who were being educated in mainstream schools reduced by 1.6% per annum. This was primarily accounted for by an annual 5.1% reduction in the proportion of children with primary SEN of SLD being educated in mainstream schools.

There was substantial variation across local authorities in the percentage of children with a primary SEN (School Action Plus or with statements) associated with learning disabilities who were placed in mainstream schools:

- for children with a primary SEN (School Action Plus or with statements) of MLD: the 10% of councils making most use of mainstream schools placed 98% or more of children with MLD in mainstream schools; the 10% of councils making least use of mainstream schools placed less than 73% of children with MLD in mainstream schools
- for children with a primary SEN (School Action Plus or with statements) 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 8% of children with SLD in mainstream schools
- for children with a primary SEN (School Action Plus or with statements) of PMLD: the 10% of councils making most use of mainstream schools placed 32% or more of children with PMLD in mainstream schools; the 20 councils (13%) making least use of mainstream schools placed no children with PMLD in mainstream schools

There were moderately strong associations across local authorities in rates of placement of children with MLD and SLD ($r = +0.32$, $p < 0.001$) and children with SLD and PMLD ($r = +0.40$, $p < 0.001$) in mainstream schools. There was no association across local authorities in rates of placement of children with MLD and PMLD ($r = +0.09$, $p = 0.30$) in mainstream schools.

Educational attainment

The ‘Children with Special Educational Needs’ series contains detailed information on the educational attainment of children with and without SEN nationally and, for some indicators, by local authority.

As would be expected, children with SEN associated with learning disabilities have markedly lower educational attainment than their peers. Attainment is measured at various stages throughout a child’s education. Key Stage 2 (KS2) refers to the stage of the national curriculum for pupils aged between 7 and 11 years. The percentage of children assessed as achieving the expected level of attainment in both English and maths at the end of KS2 is presented in Table 5.4.

Table 5.4: percentage of children assessed as achieving the expected level of attainment in both English and maths in at the end of KS2, England 2007 to 2012

	2007	2008	2009	2010	2011	2012	Compound annual growth rate
MLD	9%	12%	11%	13%	15%	20%	+17%
SLD	2%	2%	2%	2%	3%	3%	+8%
PMLD	1%	1%	-	1%	2%	1%	+0%
All pupils with SEN	29%	32%	31%	34%	35%	32%	+2%

School absence and exclusion

The 'Children with Special Educational Needs' series contains detailed information on the school attendance and exclusion of children with and without SEN nationally and, for some indicators, by local authority.

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 authorized or unauthorized:

- 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 5.5. 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 eight half-day sessions.

Table 5.5: average percentage of half-day sessions missed due to authorised and unauthorised absences, financial year 2007 to 2008 to financial year 2011 to 2012

	2007 to 2008	2008 to 2009	2009 to 2010	2010 to 2011	2011 to 2012	Compound annual growth rate
Authorised						
MLD	6.8	6.7	6.4	6.1	5.4	-5.6%
SLD	7.3	7.5	7.2	7.1	6.6	-2.5%
PMLD	12.6	13.4	13.7	13.3	12.9	+0.6%
All children	n/a	5.2	5.0	4.7	3.7	-10.7%
Unauthorised						
MLD	2.2	2.3	2.2	2.3	2.0	-2.4%
SLD	1.0	1.0	1.0	0.9	0.7	-8.5%
PMLD	0.7	0.7	0.7	0.7	0.7	0.0%
All children	n/a	1.1	1.0	1.1	0.7	-14.0%
Total						
MLD	9.0	9.0	8.6	8.3	7.4	-4.8%
SLD	8.2	8.5	8.2	8.0	7.4	-2.5%
PMLD	13.3	14.2	14.4	14.0	13.6	+0.6%
All children	6.3	6.3	6.0	5.8	4.4	-11.3%

For children with a primary SEN of SLD or PMLD, increased rates of absence were accounted for by increased rates of authorised absences. For children with a primary SEN of MLD, approaching half of the excess was unauthorised.

Persistent absentees are defined as having an overall absence rate of 15% per cent or more. This equates to 46 or more sessions of absence (authorised and unauthorised) during the year. For children with a primary SEN associated with learning disabilities, 12% of children with MLD or SLD were classified as persistent absentees, 30% of children with PMLD were classified as persistent absentees.

Reasons recorded for absences for children with a statement of SEN are presented in Table 5.6. As can be seen, illness and medical/dental appointments accounted for 57% of absences of children with MLD, 73% of absences of children with SLD and 80% of absences of children with PMLD.

Table 5.6: reasons for absences from school of children with primary SEN associated with learning disabilities, England 2011 to 2012

	MLD	SLD	PMLD	No Identified SEN
Authorised				
Illness (not medical or dental appointments)	50%	59%	64%	61%
Medical/dental appointments	7%	14%	16%	6%
Religious observance	<1%	<1%	<1%	<1%
Study leave	1%	<1%	<1%	2%
Traveller absence	1%	<1%	<1%	<1%
Agreed family holiday	4%	7%	4%	8%
Agreed extended family holiday	<1%	<1%	<1%	<1%
Excluded, no alternative provision	3%	<1%	<1%	1%
Other authorised circumstances	7%	8%	11%	5%
Unauthorised				
Family holiday not agreed	2%	1%	<1%	4%
Arrived late	2%	1%	<1%	1%
Other unauthorised circumstances	21%	7%	3%	10%
No reason yet	3%	1%	1%	2%

Exclusions

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 1 or more fixed term exclusions and who were permanently excluded is presented in Table 5.7. As can be seen, children with a primary SEN of MLD were markedly more likely to be excluded than children with no SEN. Children with a primary SEN of PMLD were less likely to be excluded than children with no SEN.

Table 5.7: percentage of children with primary SEN associated with learning disabilities excluded from school, England 2006 to 2007 to 2011 to 2012							
	2006 to 2007	2007 to 2008	2008 to 2009	2009 to 2010	2010 to 2011	2011 to 2012	Compound annual growth rate
Fixed Term							
MLD	6.8%	6.4%	n/a	5.8%	5.8%	6.3%	-1.5%
SLD	2.3%	2.0%	n/a	1.4%	1.8%	1.6%	-7.0%
PMLD	0.7%	0.6%	n/a	0.4%	0.6%	0.4%	-10.6%
Children without SEN	1.8%	1.5%	n/a	1.5%	1.5%	1.8%	0.0%
Permanent							
MLD	0.3%	0.2%	n/a	n/a	0.1%	0.2%	-7.8%
SLD	0.2%	0.0%	n/a	n/a	0.1%	0.0%	-100.0%
PMLD	0.0%	0.0%	n/a	n/a	0.0%	0.0%	0.0%
Children without SEN	0.0%	0.0%	n/a	n/a	0.0%	0.0%	0.0%

The reasons for fixed term and permanent exclusion in 2011 to 2012 of pupils with primary SEN associated with learning disabilities are given in Table 5.8.

Table 5.8: reasons given for exclusion of pupils, 2011 to 2012				
	Children without SEN	MLD	SLD	PMLD
Fixed Term				
Persistent disruptive behaviour	22%	27%	20%	16%
Physical assault against a pupil	22%	18%	20%	21%
Other	21%	16%	10%	0%
Verbal abuse/ threatening behaviour against an adult	19%	21%	18%	0%
Verbal abuse/ threatening behaviour against a pupil	4%	4%	3%	0%
Drug and alcohol related	4%	2%	0%	0%
Physical assault against an adult	2%	5%	24%	45%
Damage	2%	2%	2%	0%
Bullying	2%	1%	0%	0%
Racist abuse	2%	2%	0%	0%
Theft	2%	1%	0%	0%
Sexual misconduct	1%	1%	0%	0%
Permanent				
Persistent disruptive behaviour	26%	39%	n/a	n/a
Physical assault against a pupil	18%	13%	n/a	n/a
Other	17%	11%	n/a	n/a
Drug and alcohol related	13%	5%	n/a	n/a
Verbal abuse/ threatening behaviour against an adult	8%	10%	n/a	n/a
Physical assault against an adult	7%	12%	n/a	n/a
Verbal abuse/ threatening behaviour against a pupil	5%	5%	n/a	n/a
Theft	2%	0%	n/a	n/a
Damage	2%	0%	n/a	n/a
Bullying	1%	0%	n/a	n/a
Racist abuse	1%	0%	n/a	n/a
Sexual misconduct	1%	0%	n/a	n/a

6. Children's social care

Summary

Information from the DfE indicates that:

- at 31 March 2013, 24,686 children in England were identified as being Children in Need and to have a disability associated with learning. This represents 0.22% of the total child population in England. Variation by local authority was substantial. The number of Children in Need who had a disability associated with learning increased by 3.8% between 2012 and 2013
- at 31 March 2013, 4,470 children with SEN associated with learning disabilities had been looked after continuously for at least 12 months by the local authority. The number of looked after children with SEN associated with learning disabilities increased by 10.1% between 2012 and 2013
- nearly 1 in 3 of 'looked after' children (those in the care of the local authority) have SEN associated with learning disabilities
- the majority of looked after children with SLD (87%) and PMLD (90%) were attending special schools. The majority of looked after children with MLD (73%) were attending mainstream schools
- the risk per 1,000 children of being looked after continuously for at least 12 months by the local authority as of March 31 2013 was: 6 for all children; 22.3 for children with MLD; 31.9 for children with SLD; and 39.9 for children with PMLD

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 DfE.¹⁻⁴ 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
- 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 includes 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 2013, 24,686 children in England were identified as being in need and to have a disability associated with learning. This represents 0.22% of the total child population in England.

Table 6.1 presents data on the number of children identified as being in need and to have a disability associated with learning and related percentage of the total child population by Government Office Region at 31 March 2013.

At all points in time and in all regions the prevalence of 'learning disabilities' identified in the Children in Need census was markedly lower than: (1) the estimated prevalence of learning disabilities;⁵ (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. These observations are rather anomalous given that children with disabilities are defined as being Children in Need.

Table 6.1: number and (for 2013) percentage of Children in Need with disability associated with learning, England 31 March 2010 to 2013						
	2010	2011	2012	2013	As % of children (2013)	Compound annual growth rate (number of children)
England	25,100	26,076	23,776	24,686	0.22%	-0.6%
North East	1,331	1,724	1,456	1,564	0.30%	+5.5%
North West	3,098	2,910	2,599	2,666	0.18%	-4.9%
Yorkshire & Humber	2,487	2,700	2,511	2,477	0.22%	-0.1%
East Midlands	1,369	1,640	1,584	1,512	0.16%	+3.4%
West Midlands	2,607	2,947	2,309	2,430	0.20%	-2.3%
East of England	1,981	2,598	2,561	2,432	0.19%	+7.1%
London	3,796	4,296	3,766	3,766	0.20%	-0.3%
South East	3,397	4,091	4,192	4,412	0.24%	+9.1%
South West	2,851	3,189	2,868	3,418	0.32%	+6.2%

Variation by local authority was also substantial. The lowest performing 10% of local authorities identified 0.11% or fewer children as being in need and having a disability associated with learning. The highest performing 10% of local authorities identified 0.38% 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 DfE.⁶⁻⁹ 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 (MLD, SLD, PMLD).

Table 6.2: number and percentage of children who have been looked after continuously for at least 12 months by the local authority with SEN associated with learning disabilities, England 31 March 2010 to 2013

	Number				As % of looked after children				Compound Annual Growth Rate 2011-13 (Number)
	2010	2011	2012	2013	2010	2011	2012	2013	
England									
MLD	3,000	3,080	2,980	3,080	21%	21%	20%	19%	0.0%
SLD	680	680	750	970	5%	5%	5%	6%	+19.4%
PMLD	n/a	310	320	420	n/a	2%	2%	3%	+16.4%
Total	n/a	4,070	4,060	4,470	n/a	27%	27%	30%	+4.8%

Nearly 1 in 3 of looked after children have SEN associated with learning disabilities. Using the number of children on school rolls in 2013 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 2013 was:

- 6 for all children
- 22.3 for children with MLD
- 31.9 for children with SLD
- 39.9 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 (73%) were attending mainstream schools.

7. Adult social care

Summary

This section summarises information collected by the Information Centre for Health and Social Care on social care services utilised by adults with learning disabilities.

Regarding non-healthcare accommodation for adults with learning disabilities in England:

- in 2012 to 2013, local authorities reported that 74% of the 140,015 adults with learning disabilities known to them were living in some form of settled accommodation, with the most common type of accommodation being settled mainstream housing with family/friends (50,930 people)
- in 2012 to 2013, there were 31,150 adults aged 18+ with learning disabilities in local authority funded independent sector residential care; 1,945 adults in local authority staffed residential care; 1,930 adults in nursing care and 4,005 adults in adult placement schemes
- from 2011 to 2012 to 2012 to 2013, with the exception of adult placements (increase 1.1%), there were decreases in the number of adults with learning disabilities in all other forms of residential care (decrease 3.5%)
- in 2012 to 2013, local authority gross current expenditure relating to residential services for adults with learning disabilities aged 18 to 64 years was:
 - £2 billion on residential care (a 0.9% real terms decrease from 2011 to 2012)
 - £867.5 million on supported/other accommodation (a 13.6% real terms increase from 2011 to 2012)
 - £91.1 million on nursing care (a 5.9% real terms increase from 2011 to 2012)
 - £108.8 million on Supporting People (a 12.5% real terms decrease from 2011 to 2012)

Regarding community social care services in England:

- in 2012 to 2013 local authorities reported 114,265 adults with learning disabilities aged 18+ using some form of social care community service (with small but consistent year-on-year increases from 2005 to 2006)
- regarding day services, in 2012 to 2013 there were 51,300 adults with learning disabilities using local authority funded day services (with small but consistent year-on-year decreases from 2005 to 2006). In 2012 to 2013, local authorities spent £681.5 million on day services for adults with learning disabilities aged 18 to 64 years, a real terms decrease of 4.5% from 2011 to 2012
- regarding home care services, in 2012 to 2013 there were 42,200 adults with learning disabilities using local authority funded home care services (with numbers virtually static from 2010 to 2011 to 2012 to 2013). In 2012 to 2013, local authorities

spent £655.5 million on home care services for adults with learning disabilities aged 18 to 64 years (expenditure static from 2011 to 2012)

- regarding professional support, in 2012 to 2013 there were 22,400 adults with learning disabilities using local authority funded professional support, a decrease of 37% from 2010 to 2011. No specific data is available on local authority spending for professional support
- regarding equipment and adaptations, in 2012 to 2013 there were 9,860 adults with learning disabilities receiving some support for equipment and/or adaptations (with numbers virtually static from 2010 to 2011 to 2012 to 2013). In 2012 to 2013, local authorities spent £4.5 million on equipment and adaptations for adults with learning disabilities aged 18 to 64, a real terms decrease of 29% from 2010 to 2011 to 2012 to 2013
- regarding meals, in 2012 to 2013 450 adults with learning disabilities received a local authority funded meals service (with consistent year-on-year decreases from 2005 to 2006), with local authorities spending £0.5 million on meals services for adults with learning disabilities aged 18 to 64
- in 2012 to 2013 21,700 adults with learning disabilities were using some form of local authority funded 'other' service, a decrease of 5% from 2011 to 2012. Local authorities spent £144.7 million on 'other' services for adults with learning disabilities aged 18 to 64 in 2012 to 2013, a real terms decrease of 14% from 2011 to 2012 to 2012 to 2013

Regarding social care assessments and reviews in England:

- in 2012 to 2013 12,615 new adult clients with learning disabilities had a completed assessment, with numbers fluctuating year-on-year but fairly static from 2009 to 2010
- in 2012 to 2013 92,960 existing adult clients with learning disabilities had a completed review, a decrease of 9% from 2010 to 2011
- in 2012 to 2013 local authorities spent £292.6 million on assessment and care management for adults with learning disabilities aged 18 to 64, a real terms increase of 1% from 2011 to 2012

Regarding direct payments and self-directed support in England:

- in 2012 to 2013 78,820 adults with learning disabilities were reported by local authorities to be making use of a direct payment and/or self-directed support, an increase of 85% from 2010 to 2011
- in 2012 to 2013 49,035 of these 78,820 adults (62%) were using self-directed support in the form of council-services only, an increase of 148% from 2010 to 2011
- in 2012 to 2013 18,600 of these 78,820 adults (24%) were using direct payments only (either as part of self-directed support or separately), an increase of 2% from 2010 to 2011
- in 2012 to 2013 local authorities spent £385 million on direct payments for adults with learning disabilities aged 18 to 64 years, a real terms increase of 48% from 2010 to 2011

Regarding service user experiences of social care in England:

- in the Personal Social Services Adult Social Care Survey (2011 to 2012 and 2012 to 2013), 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 any other group of people using social care. A range of factors, including methodological factors, are likely to account for these differences

Introduction

Statistics related to social care support for people with learning disabilities are largely publicly available through the NHS Information Centre. Social care statistics are published in a set of web-based interactive tools labelled National Adult Social Care Intelligence Service (NASCIS). Councils, with social services responsibilities, mainly collect the data.

Some aspects of the data collection system for social care have changed over time. As such, the reporting of consistent data over time was not possible for all the information. In addition, there can be minor inconsistencies between different sets of national statistics concerning very similar types of social care service. This report describes the inconsistencies between data from different sources, rather than attempting to reconcile them.

As far as possible, this section is organised by domains of social care services for people with learning disabilities, rather than by social care dataset. This leads to some repetition of datasets across social care service domains, but places all the sources of data concerning service types together. The following headings are used:

- residential social care Services for adults with learning disabilities
- community social care services for adults with learning disabilities
- day services
- other community services
- social care assessment and review processes for adults with learning disabilities
- direct payments and personal budgets for adults with learning disabilities
- service user experiences of social care

Residential social care services

There is a large amount of data available related to residential services for adults with learning disabilities in England, although there do appear to be some inconsistencies between different indicators.

Table 7.1 below presents data on the number of adults with learning disabilities in England known to local authorities in all forms of accommodation (including non-residential service settings) between 1 April 2012 and 31 March 2013 (ASC-CAR Table L2). This indicator was first collected for 2008 to 2009, however, due to large fluctuations in numbers reported between 2008 to 2009 and 2009 to 2010, which suggest improved reporting from local authorities, only data starting from 2009 to 2010 is reported here, although it is important to

note that there are still substantial year-on-year fluctuations in some categories (<http://nascis.ic.nhs.uk/Index.aspx>).

In 2012 to 2013, 140,015 adults with learning disabilities were reported by local authorities to be in some form of accommodation, although this total figure is considerably higher than the total obtained by adding the number of people in settled and non-settled accommodation (134,190 people). There was a reported 0.9% compound annual growth rate (CAGR) increase in this total from 2009 to 2010 to 2012 to 2013, although it is unclear if this is a reflection of better recording of the accommodation of adults with learning disabilities by local authorities over time.

In 2012 to 2013, the largest single category of accommodation was settled mainstream housing with family/friends (50,930 people, a CAGR increase of +7% from 2009/2010), with a further 770 people staying with family/friends as a short-term guest (a CAGR increase of +1.1% from 2009 to 2010).

Substantial numbers of adults were living in registered care homes (26,625 people, a CAGR increase of +2.4% from 2009 to 2010), nursing homes (1,665 people, a CAGR decrease of -3.1% from 2009 to 2010) or healthcare residential facilities or hospitals (1,075 people, a CAGR decrease of -6% from 2009 to 2010), with substantial additional numbers of people living in supported accommodation or group homes (24,700 people, a CAGR increase of +11.8% from 2009 to 2010).

There were also substantial numbers of adults with tenancies, either with local authorities or other organisations (15,190 people, a CAGR increase of +4.1% from 2009 to 2010) or with private landlords (5,030 people, a CAGR increase of +10.7% from 2009 to 2010).

Table 7.1: number of adults with learning disabilities in England in accommodation 1 April- 31 March

	Year				Compound annual growth rate 2009 to 2010 to 2012 to 2013
	2009 to 2010	2010 to 2011	2011 to 2012	2012 to 2013	
Rough sleeper/squatting	40	25	25	25	-14.5%
Night shelter/emergency hostel/direct access hostel (temp accomm accepting self-referrals)	70	55	55	65	-2.4%
Refuge	10	10	10	10	0.0%
Placed in temp accomm by council (inc homelessness settlement) eg B&B,	210	195	170	305	+13.3%
Staying with family/ friends as short-term guest	745	625	765	770	+1.1%
Acute/long stay healthcare residential facility or hospital	1295	1045	1230	1075	-6.0%
Registered care home	24830	23465	26195	26625	+2.4%
Registered nursing home	1830	1290	1610	1665	-3.1%
Prison/young offenders institution/detention centre	30	30	45	40	+10.1%
Other temp accomm	705	1245	1150	665	-1.9%
Total non-settled accommodation	29765	27990	31255	31245	+1.6%
Owner occupier/shared ownership scheme	2755	2340	2885	2640	-1.4%
Tenant – LA/arms length mgt org/registered social landlord/housing assn	13460	13395	14785	15190	+4.1%
Tenant – private landlord	3710	4010	4605	5030	+10.7%
Settled mainstream housing with family/ friends (inc flat-sharing)	41590	41205	48785	50930	+7.0%
Supported accomm/ supported lodgings/ supported group home	17655	17610	21420	24700	+11.8%
Adult placement scheme	2695	2675	3805	3415	+8.2%
Approved premises for offenders released from prison or under probation supervision	35	40	205	35	0.0%
Sheltered housing/ extra care housing/ other sheltered housing	640	675	835	985	+15.5%
Mobile accomm for Gypsy/Roma and Traveller community	20	35	25	25	+7.7%
Total settled accommodation	82565	81985	97360	102945	+7.6%
Total	136350	138995	139090	140015	+0.9%
Data source: NASCIS ASC -CAR (adult social care – combined activity returns) Table L2					

Fewer numbers of adults were living in owner-occupied or shared ownership accommodation (2,640 people, a CAGR decrease of -1.4% from 2009 to 2010) or adult placement schemes (3,415 people, a CAGR increase of +8.2% from 2009 to 2010).

Across England, in 2012 to 2013, 74% of adults known to councils with adult social services responsibilities were reported to be living in settled accommodation at the time of their last assessment or review, compared with 61% in 2009 to 2010.

According to local authorities, smaller numbers of adults with learning disabilities in 2012 to 2013 were living in a variety of other accommodation arrangements, including prisons and other offender institutions (40 people) and approved premises for offenders (35 people). 25 people were reported as sleeping rough or squatting, with a further 65 people in temporary hostel accommodation. 25 people were reported to be in mobile accommodation for the Gypsy/Roma and Traveller community. A further 665 people were reported by local authorities to be in 'other' temporary accommodation.

Settled accommodation includes: owner occupier/shared ownership scheme (where tenant purchases percentage of home value from landlord); tenant - local authority/arms length management organisation/registered social landlord/housing association; tenant - private landlord; settled mainstream housing with family/friends (including flat-sharing); supported accommodation/supported lodgings/supported group home (accommodation supported by staff or resident caretaker); adult placement scheme; approved premises for offenders released from prison or under probation supervision (eg probation hostel); sheltered housing/extra care sheltered housing/other sheltered housing; mobile accommodation for gypsy/Roma and traveller community.

Non-settled accommodation includes: rough sleeper/squatting; night shelter/emergency hostel/direct access hostel (temporary accommodation accepting self referrals); refuge; placed in temporary accommodation by local authority (including homelessness resettlement) - eg bed and breakfast; staying with family/friends as a short term guest; acute/long stay healthcare residential facility or hospital (eg NHS or independent general hospitals/clinics, long stay hospitals, specialist rehabilitation/recovery hospitals); registered care home; registered nursing home; prison/young offenders institution/detention centre; and other temporary accommodation.

Table 7.2 below presents data on the number of adults with learning disabilities in England receiving council-funded residential support in the form of adult placements, nursing care or residential care. This was broken down by age group (18 to 64 years and 65+ years) and was reported annually from 2005 to 20065 to 2012 to 2013.

When interpreting Table 7.2, it is important to note that an estimated 1,840 adults with learning in residential care in 2011 to 2012 were already in residential care under NHS funding, but transferred to local authority responsibility (with funding also transferring) under Valuing People Now (VPN) for 2011 to 2012⁵. Therefore Table 7.2 also includes an estimated total of adults with learning disabilities in local authority residential care for 2011 to 2012 and 2012 to 2013 consistent with previous years.

⁵ Health and Social Care Information Centre (2013). Community Care Statistics, Social Services Activity – England, 2011-12, Final Release. <https://catalogue.ic.nhs.uk/publications/social-care/activity/comm-care-soci-serv-act-eng-11-12-fin/comm-care-stat-eng-2011-12-soci-serv-act-rep.pdf>

Figure 7.1 below also presents the data for adults aged 18+ as a bar chart.

Across all adult age groups (see also Figure 7.1), by far the most common form of residential support was independent sector residential care (31,150 adults aged 18+ in 2012 to 2013; 79.8% of the total). There were smaller numbers living in adult placements (4,005 people; 10.3%), local authority staffed residential care homes (1,945 people; 5%) or nursing care (1,930 people; 4.9%). From 2005 to 2006, the proportion of adult placements has increased (from 4.5% to 10.3% of all local authority supported residential places), the proportion of local authority staffed residential places has decreased (from 9.1% to 5%) and the proportion of nursing care places has stayed low (6.2% to 4.9%). The proportion of independent residential care places has stayed high over this time period (from 80.1% in 2005 to 2006 to 79.8% in 2012 to 2013).

The total number of adults with learning disabilities aged 18+ supported in residential care reduced slightly from financial year 2005 to 2006 to financial year 2010 to 2011 (39,400 to 38,365 adults; a CAGR decrease of -0.5%), increased to 40,270 adults in 2011 to 2012 if transfers under VPN are included, but decreased again to 39,025 adults in 2012 to 2013, however, excluding such transfers resulted in a consistent trend from financial year 2005 to 2006 to financial year 2012 to 2013 of continued reductions in residential care places (CAGR decrease -0.8% per year).

Table 7.2: number of adults with learning disabilities in England supported by local authorities at 31 March in residential care

	Year								Compound annual growth rate 2005 to 2006 to 2012 to 2013
	2005 to 2006	2006 to 2007	2007/ to 2008	2008/ to 2009	2009 to 2010	2010 to 2011	2011 to 2012 ⁶	2012 to 2013 ²	
Aged 18 to 64									
Adult placement	1670	2225	2255	3055	3195	3265	3595	3580	+11.5%
Nursing care	1840	1865	1735	1640	1560	1505	1290	1240	-5.5%
Independent residential care	28550	28340	27630	27120	26455	26410	27045	26260	-1.2%
Council staffed residential care	3200	3075	2895	2735	2525	2265	1990	1690	-8.7%
Total	35260	35510	34520	34550	33735	33445	33920	32770	-1.0%
Aged 65+									
Adult placement	170	230	220	290	330	335	365	425	+14.0%
Nursing care	605	585	580	510	915	540	745	690	+1.9%
Independent residential care	3255	3325	3515	3490	3855	3750	4915	4890	+6.0%
Council staffed residential care	400	400	370	395	345	290	325	255	-6.2%
Total	4435	4535	4685	4685	5445	4915	6350	6255	+5.0%
Total aged 18+									
Adult placement	1790	2455	2475	3345	3525	3600	3960	4005	+12.2%
Nursing care	2440	2450	2315	2150	2475	2045	2035	1930	-3.3%
Independent residential care	31575	31660	31145	30610	30310	30165	31960	31150	-0.2%
Council staffed residential care	3595	3475	3265	3130	2870	2560	2315	1945	-8.4%
Total	39400	40040	39200	39235	39185	38365	40270	39025	-0.1%
(VPN transfers)							(-1840)	(-1840)	
Total without VPN transfers							38430	37185	-0.8%

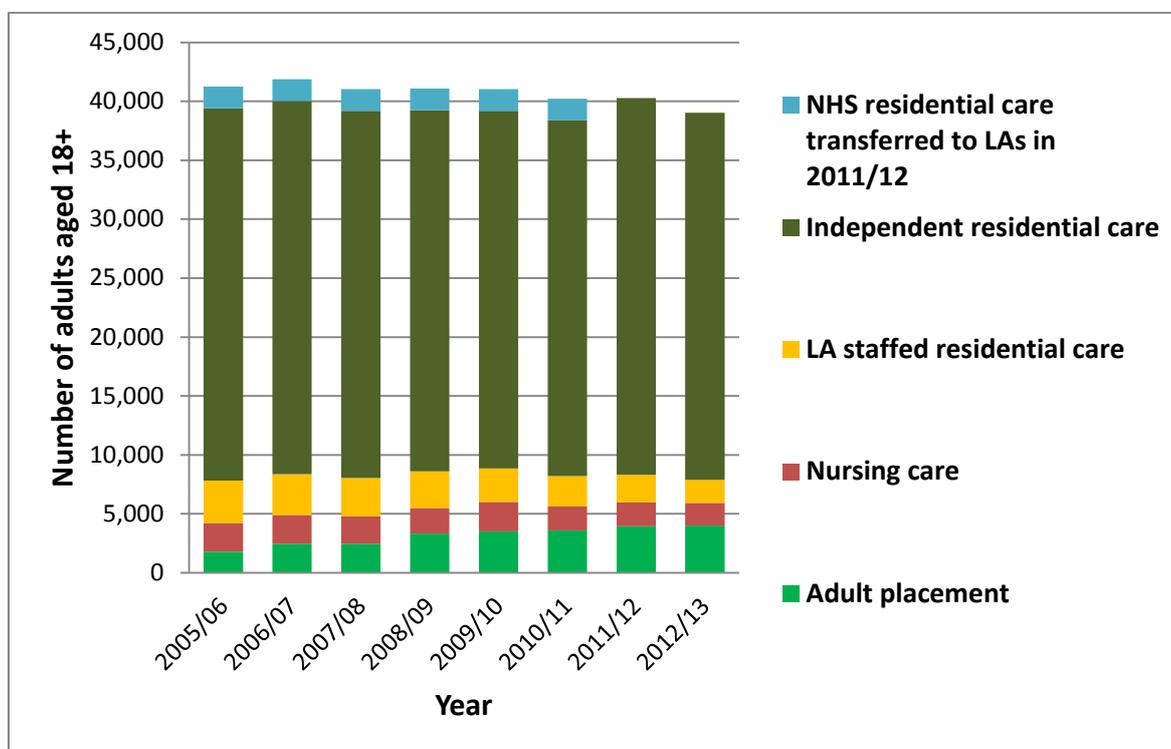
Data source: NASCIS ASC-CAR (Adult Social Care – Combined Activity Returns) Table S1

⁶ The total figure of 40,270 adults with learning disabilities in residential care for 2011 to 2012 and 2012 to 2013 includes 1,840 adults with learning disabilities already in residential care where their funding transferred from the NHS to local authorities under VPN.

The number of adults aged 18+ in adult placements increased substantially from financial year 2005 to 2006 to financial year 2012 to 2013 (CAGR increase +12.2%), however, there were decreases over this time period in the number of adults in nursing care (CAGR decrease - 3.3%) and in local authority staffed residential care (CAGR decrease -8.4%). The number of adults in independent sector residential care stayed virtually static (CAGR decrease -0.2%). These figures include unspecified numbers of adults with learning disabilities transferred under VPN.

From 2011 to 2012 to 2012 to 2013 there was an overall decrease of 3.1% in the number of adults with learning disabilities supported by local authorities in residential care; with the exception of adult placements there were decreases in all other forms of residential care for adults aged 18 to 64 and adults aged 65+.

Figure 7.1: number of adults with learning disabilities in England supported by local authorities at 31 March in residential care.



The same dataset was also used as the basis for Table 7.3 below. This table presents 2012 to 2013 data for the number of adults with learning disabilities in local authority supported residential care at 31 March across nine English regions and for England in total (including transfers under VPN).

There was considerable regional variation in the total number of adults with learning disabilities in residential care as a proportion of the total adult population (from 55 per 100,000 in the North West to 110 per 100,000 in the South West; for England the figure is 95 per 100,000).

Among all adults aged 18+, there was considerable variation in the proportions of local authority supported residential care places taken up by adult placements (from 4.3% in the Eastern region to 21.1% in the North West; for England the overall percentage is 10.3%); by nursing care (from 2.5% in the South East to 9.1% in the East Midlands; for England the

overall percentage is 4.9%); by independent sector residential care (from 66.4% in the North West to 91% in the Eastern region; for England the overall percentage is 79.8%); and by local authority staffed residential care (from 2.1% in the Eastern Region to 9.3% in the North East; for England the overall percentage is 5%).

There was less variation in the percentage of adults with learning disabilities in any type of local authority supported residential care who are aged 65 or over (from 14% in Yorkshire & Humber to 18.6% in London; for England the overall percentage is 16%).

Table 7.3: number of adults with learning disabilities in England regions supported by local authorities at 31 March 2013 in residential care

	Area									Total for England
	East Midlands	Eastern	London	North East	North West	South East	South West	West Midlands	Yorkshire and Humber	
Aged 18 to 64										
Adult placement	330	175	430	225	570	675	390	345	450	3580
Nursing care	235	75	105	75	180	95	95	185	195	1240
Independent residential care	2490	3325	4270	1275	1700	4990	3060	2985	2160	26260
Council staffed residential care	100	85	150	180	150	280	370	205	170	1690
Total	3150	3655	4955	1755	2595	6040	3915	3720	2980	32770
Aged 65+										
Adult placement	35	10	30	20	70	100	60	40	20	425
Nursing care	85	40	145	45	60	85	80	80	70	690
Independent residential care	430	580	885	310	300	845	640	550	350	4890
Council staffed residential care	35	5	30	20	15	50	30	30	45	255
Total	580	635	1130	395	445	1075	805	705	485	6255
Total aged 18+										
Adult placement	365	185	460	245	640	775	450	385	470	4005
Nursing care	320	115	250	120	240	180	175	265	265	1930
Independent residential care	2920	3905	5155	1585	2000	5835	3700	3535	2510	31150
Council staffed residential care	135	90	180	200	165	330	400	235	215	1945
Total	3530	4290	6085	2155	3040	7115	4720	4425	3465	39025
Total aged 18+ in residential care (independent or la) per 100,000 population	105	90	95	105	55	105	110	100	85	95
Data source: NASCIS ASC-CAR (Adult Social Care – Combined Activity Returns) Table S1										

Table 7.4 presents data on the number of adults with learning disabilities aged 18 to 64 and aged 65+ who had been permanently admitted to local authority supported residential care (excluding group homes) between 1 April and 31 March in each year from financial year 2005 to 2006 to financial year 2012 to 2013.

Table 7.4: number of adults with learning disabilities aged 18+ in England permanently admitted to local authority supported residential care (excluding group homes) 1 April- 31 March

	Year								Compound annual growth rate 2005 to 2006 to 2012 to 2013
	2005 to 2006	2006 to 2007	2007 to 2008	2008 to 2009	2009 to 2010	2010 to 2011	2011 to 2012 ⁷	2012 to 2013	
Aged 18 to 64									
Adult placement	160	315	295	465	430	480	505	535	+18.8%
Nursing care	205	140	125	115	125	140	155	135	-5.8%
Residential care independent	1965	1850	1655	1575	1605	1770	3005	1,605	-2.9%
local auth.	1835	1725	1565	1510	1545	1675	2920	1,550	-2.4%
	130	125	90	65	60	95	85	55	-11.6%
Total	2330	2305	2075	2155	2160	2390	3665	2,275	-0.3%
Aged 65+									
Adult placement	10	15	10	25	30	30	20	45	+24.0%
Nursing care	95	70	55	50	80	235	115	325	+19.2%
Residential care independent	180	245	160	155	295	440	770	620	+19.3%
local auth.	165	210	145	135	260	430	745	605	+20.4%
	15	35	15	20	35	10	25	10	-5.6%
Total	285	330	225	230	405	705	900	985	+19.4%
Total aged 18+									
Adult placement	160	330	305	490	460	505	525	580	+20.2%
Nursing care	295	210	180	160	205	375	270	460	+6.6%
Residential care independent	2120	2100	1815	1730	1900	2210	3775	2,225	+0.7%
local auth.	1975	1940	1710	1645	1805	2105	3665	2,155	+1.25%
	145	160	105	85	95	105	110	65	-10.8%
Total	2575	2645	2305	2380	2565	3090	4565	3,260	+3.4%
Vpn transfers							(-1840)		
Total without vpn transfers							2725		

⁷ The total figure of 4,565 permanent admissions to residential care include 1,840 adults with learning disabilities already in residential care but counted as new permanent admissions because their funding transferred from the NHS to local authorities under VPN.

Data source: NASCIS ASC-CAR (Adult Social Care – Combined Activity Returns) Table S3

When interpreting Table 7.4, it is important to note that an estimated 1,840 adults with learning disabilities counted as permanent admissions in 2011 to 2012 were already in residential care under NHS funding, but transferred to local authority responsibility under VPN for 2011 to 2012⁸. Therefore Table 7.4 also includes an estimated 'real' total of permanent admissions to local authority residential care for 2011 to 2012. Obviously, permanent admissions for 2012 to 2013 revert to their usual pattern.

Trends over time show emerging differences in the number of permanent admissions between adults aged 18 to 64 and adults aged 65+. For adults aged 18 to 64, the number of permanent admissions to all forms of local authority supported residential care has decreased from financial year 2005 to 2006 to financial year 2012 to 2013 (with the exception of adult placements, which continue to increase in number). However, for adults aged 65+, the number of permanent admissions to all forms of local authority supported residential care (with the exception of local authority staffed residential care) has increased from financial year 2005 to 2006 to financial year 2012 to 2013, with particularly sharp recent rises in permanent admissions to independent sector residential care and nursing care.

From financial year 2005 to 2006 to financial year 2009 to 2010, the proportion of permanent admissions who were adults aged 65+ was fairly consistent, at around 10% of all permanent admissions. By 2012 to 2013, this proportion had risen to 30.2% of permanent admissions being adults aged 65+.

Table 7.5 below presents data from Table P2F from the NASCIS RAP dataset. This is a consistent dataset up to 2012 to 2013 on the total number of adults with learning disabilities using short-term residential services (this does not include respite care) financially supported by local authorities.

In 2012 to 2013, 4,485 adults with learning disabilities were using local authority funded short-term residential services, the vast majority of whom (93.8%) were adults aged 18 to 64.

From financial year 2005 to 2006 to financial year 2012 to 2013, there was a decrease in the number of adults with learning disabilities aged 18 to 64 using short-term residential services (CAGR decrease -3.8%). There was a small increase in the number of adults with learning disabilities aged 65+ using these services (CAGR increase +1%), with a net overall decrease over time (CAGR decrease -3.5%). There are, however, considerable fluctuations over time, with a rapid rise to a peak in 2007 to 2008 followed by a rapid decrease to 2012 to 2013.

⁸ Health and Social Care Information Centre (2013). Community Care Statistics, Social Services Activity – England, 2011 to 2012, Final Release. <https://catalogue.ic.nhs.uk/publications/social-care/activity/comm-care-soci-serv-act-eng-11-12-fin/comm-care-stat-eng-2011-12-soci-serv-act-rep.pdf>

Table 7.5: total number of adults with learning disabilities in England aged 18+ using short-term residential services supported by local authorities

	Year								Compound annual growth rate 2005 to 2006 to 2012 to 2013
	2005 to 2006	2006 to 2007	2007 to 2008	2008 to 2009	2009 to 2010	2010 to 2011	2011 to 2012	2012 to 2013	
Age 18 to 64	5505	6185	7500	7230	5745	6075	5435	4205	-3.8%
Age 65+	265	310	470	380	325	290	320	285	+1.0%
Total	5770	6495	7970	7610	6070	6365	5755	4485	-3.5%

Data source: NASCIS RAP (Referrals, Assessments and Packages of Care) Table P2F

Table 7.6 presents data on the gross current expenditure of local authorities on personal social services by financial year (April to March) concerning residential services for adults with learning disabilities aged under 65. Specific data for adults with learning disabilities aged 65 or over is not available (all adults aged 65 or over are placed in a single older people category).

When interpreting all expenditure tables, it is crucial to note that gross expenditure costs for 2011 to 2012 include costs transferred from the NHS to social services under VPN (for people with learning disabilities). The report 'Personal Social Services: Expenditure and Unit Costs England 2011-12 – Final Release' (<https://catalogue.ic.nhs.uk/publications/social-care/expenditure/pss-exp-eng-11-12-fin/pss-exp-eng-11-12-fin-rpt.pdf>) estimates that the funding transferred from the NHS to local authorities under VPN totalled £777 million. Furthermore, under a simultaneous NHS transfer scheme from PCTs to local authorities the report estimates that a further £95 million was transferred from the NHS to local authorities for services for adults with learning disabilities, 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 financial year 2010 to 2011 to financial year 2011 to 2012 of £880 million is more than 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.

In 2012 to 2013, by far the largest component of local authority expenditure relating to residential services for adults with learning disabilities aged under 65 was in residential placements (£2 billion). This was followed by supported and other accommodation (£868 million) then nursing care placements (£91 million). Supporting People expenditure in 2011 to 2012 was £109 million.

In terms of change over time from financial year 2005 to 2006 to financial year 2010 to 2011, gross expenditure on supported and other accommodation showed a compound annual growth rate (adjusted for inflation) of +16.9%, however, gross expenditure on nursing care placements (CAGR decrease adjusted for inflation -3.6%), residential care placements (CAGR decrease adjusted for inflation -0.9%) and supporting people (CAGR decrease adjusted for inflation -8.2%) all decreased over this time period.

From financial year 2010 to 2011 to financial year 2011 to 2012, with the exception of supporting people expenditure (which continued to decrease from financial year 2010 to 2011 to financial year 2011 to 2012), there were apparent increases in expenditure on all forms of residential personal social services for adults with learning disabilities aged under 65, although these increases are likely to be wholly accounted for by transfers of NHS funding into local authority budgets.

From financial year 2011 to 2012 to financial year 2012 to 2013, there were substantial real terms decreases in expenditure on residential care placements (CAGR decrease adjusted for inflation -0.9%) and supporting people (CAGR decrease adjusted for inflation -12.5%). There were substantial real terms increases in expenditure on supported and other accommodation (CAGR increase adjusted for inflation +13.6%) and nursing care placements (CAGR increase adjusted for inflation +5.9%).

Table 7.6: local authority gross current expenditure relating to residential personal social services for adults with learning disabilities aged under 65 (in millions)

Gross Current Expenditure (in millions)	Year								CAG rate constant prices 2005 to 2006 to 2011 to 2013 ⁹
	2005 to 2006	2006 to 2007	2007 to 2008	2008 to 2009	2009 to 2010	2010 to 2011	2011 to 2012 ¹⁰	2012 to 2013	
Nursing care placements	77.1	72.5	65.9	73.0	73.7	74.6	86.2	91.1	+0.9%
Residential care placements	1393.6	1459.1	1527.3	1578.2	1583.5	1546.1	2019.9	2000.1	+3.7%
Supported and other accommodation	191.2	228.3	268.8	334.4	397.7	483.3	764.5	867.5	+22.2%
Supporting people	196.7	171.2	162.5	157.2	161.3	148.8	124.5	108.8	-9.5%

Data source: NASCIS PSSEX (Personal social services expenditure data) Gross Current Expenditure

Figure 7.2 below presents this expenditure in bar chart form, also adding all other local authority expenditure on supporting adults with learning disabilities aged 18 to 64 and, for financial year 2005 to 2006 to financial year 2010 to 2011, the estimated £872 million per year NHS expenditure on services for adults with learning disabilities transferred to local authorities in 2011 to 2012. This figure is not adjusted for inflation.

Figure 7.2: local authority gross current expenditure on support for adults with learning disabilities aged 18 to 64 (also adds in additional estimated £872 million per year NHS expenditure on support for adults with learning disabilities transferred to local authorities in 2011 to 2012)

⁹ Adjusted for inflation using the personal social services, all sectors, adults only, pay and prices index (excluding capital) (inflation indices table 16.4.1) from Curtis, L. (2013) *Unit Costs of Health and Social Care 2013*. Personal Social Services Research Unit, University of Kent, Canterbury. <http://www.pssru.ac.uk/project-pages/unit-costs/2013/#sections>

¹⁰ Gross expenditure costs for 2011 to 2012 include costs transferred from the NHS to social services under VPN (for people with learning disabilities) and the NHS transfer. The report Personal Social Services: Expenditure and Unit Costs England 2011-12 – Final Release (<https://catalogue.ic.nhs.uk/publications/social-care/expenditure/pss-exp-eng-11-12-fin/pss-exp-eng-11-12-fin-rpt.pdf>) estimates that the funding transferred from the NHS to local authorities concerning all services for adults with learning disabilities totalled £872 million.

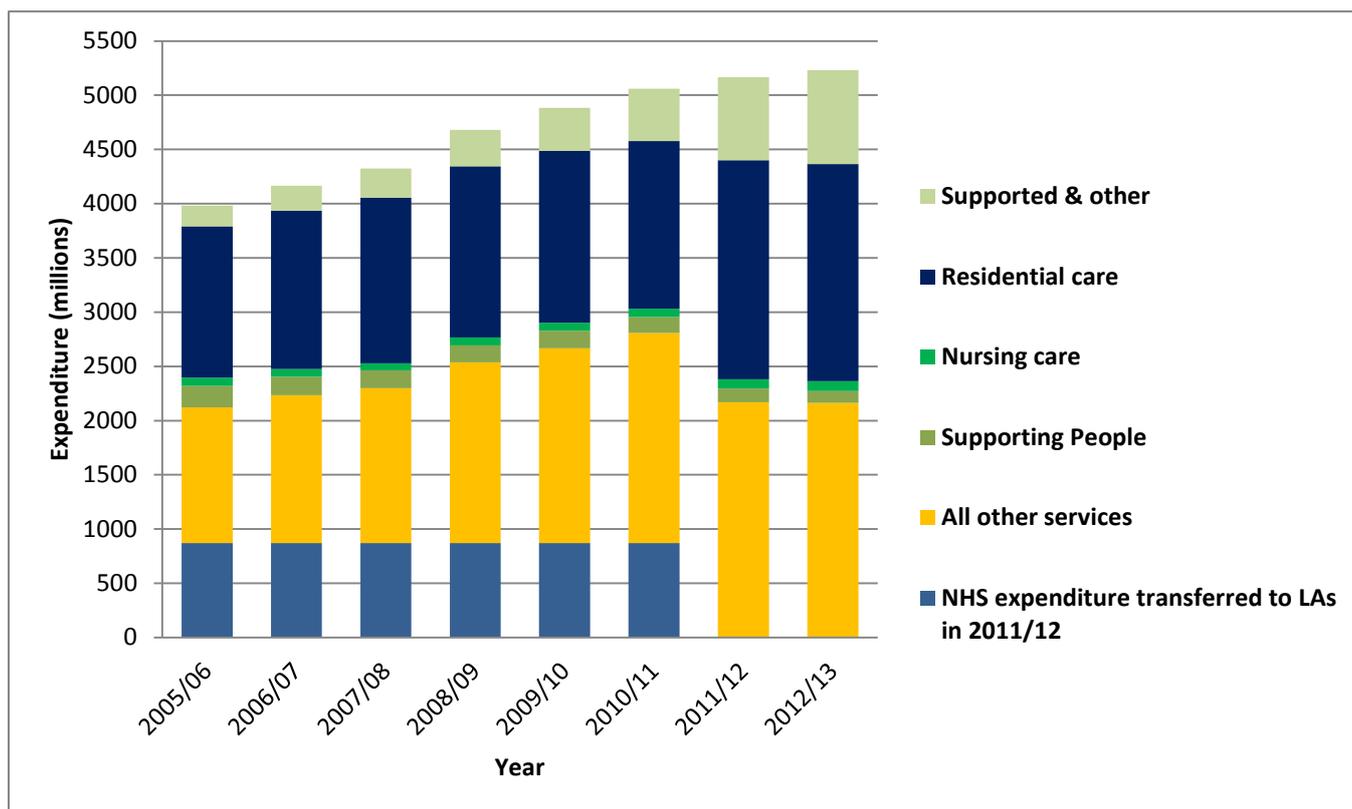


Table 7.7 below presents data on the unit costs per week of expenditure by local authorities by financial year (April to March) concerning residential services for adults with learning disabilities aged under 65. Due to changes in the way that social care information was collected, unit cost data for years before 2007 to 2008 is not comparable with data presented for this year onwards, so comparable data for financial year 2007 to 2008 to financial year 2012 to 2013 is presented in the table.

Table 7.7: local authority unit costs per week of residential personal social services for adults with learning disabilities aged under 65							
Unit Costs	Year						Compound annual growth rate at constant prices 2007 to 2008 to 2012 to 2013
	2007 to 2008	2008 to 2009	2009 to 2010	2010 to 2011	2011 to 2012	2012 to 2013	
Nursing care	852	992	1108	1196	1183	1303	+8.0%
Residen-tial care	1061	1132	1224	1277	1315	1343	+4.0%

Data Source: NASCIS PSSEX (Personal social services expenditure data) Unit Costs

In 2012 to 2013, the average unit cost of nursing care for adults with learning disabilities aged under 65 was £1,303 per week (£67,756 per year). This was a compound annual growth rate increase (taking into account inflation) of 8% per year from 2007 to 2008.

In 2012 to 2013, the average unit cost of residential care for adults with learning disabilities was £1,343 per week (£69,836 per year). This was a compound annual growth rate (taking into account inflation) of 4% per year.

Community social care services: people supported

There is a substantial amount of data available concerning community services for adults with learning disabilities in England.

Table 7.8 presents data from Table P2F from the NASCIS RAP dataset. This is a consistent dataset up to 2012 to 2013 on the total number of adults with learning disabilities receiving local authority funded community services, broken down into broad age bands. These total numbers include people using direct payments and personal budgets (see later section), but do not include people using residential services.

In 2012 to 2013 114,265 adults with learning disabilities used local authority funded community services. The vast majority were aged 18 to 64 (91.8%). Overall, the number of adults with learning disabilities steadily increased since 2005 to 2006 (CAGR increase +1.5% per year). The rate of increase was greater for adults aged 65+ (CAGR increase +4.6% per year) than for adults aged 18 to 64 (CAGR increase +1.2% per year).

Table 7.8: total number of adults with learning disabilities in England aged 18 to 64 and 65+ receiving community services supported by local authorities (this category does not include community-based residential services)

	Year								Compound Annual Growth Rate 2005 to 2006 to 2012 to 2013
	2005 to 2006	2006 to 2007	2007 to 2008	2008 to 2009	2009 to 2010	2010 to 2011	2011 to 2012	2012 to 2013	
Adults aged 18 to 64	96,280	99,400	101,440	102,145	102,985	103,800	104,320	104,840	+1.2%
Adults aged 65+	6,870	7,740	9,310	8,080	8,130	8,405	9,185	9,425	+4.6%
Total adults aged 18+	103,150	107,140	110,745	110,225	111,115	112,205	113,505	114,265	+1.5%

Data source: NASCIS RAP (Referrals, Assessments and Packages of Care) Table P2F

Day services

Within the community social care services statistics, there are 2 major sources of data relating to day services for adults with learning disabilities.

Table 7.9 presents data from Table P2F from the NASCIS RAP dataset. This is a consistent dataset up to 2012 to 2013 on the total number of adults with learning disabilities who at any point in each year have used day services financially supported by local authorities.

Table 7.9: total number of adults with learning disabilities who at some time in the year used day services supported by local authorities (England, aged 18+)

	Year								Compound annual growth rate 2005 to 2006 to 2012 to 2013
	2005 to 2006	2006 to 2007	2007 to 2008	2008 to 2009	2009 to 2010	2010 to 2011	2011 to 2012	2012 to 2013	
Age 18 to 64	55,000	54,500	54,465	54,100	49,695	48,985	48,315	47,815	-2.0%
Age 65+	3,020	2,995	3,455	3,365	3,145	3,165	3,395	3,480	+2.1%
Total	58,020	57,495	57,920	57,465	52,840	52,150	51,710	51,300	-1.7%

Data source: NASCIS RAP (Referrals, Assessments and Packages of Care) Table P2F

In 2012 to 2013 51,300 adults with learning disabilities were using local authority funded day services, the vast majority of whom (93.2%) were adults aged 18 to 64.

From financial year 2005 to 2006 to financial year 2012 to 2013, there was a consistent decrease in the number of adults aged 18 to 64 using day services (CAGR decrease -2% per year). The number of adults aged 65+ using day services fluctuated over this time period, with an overall increase from financial year 2005 to 2006 to financial year 2012 to 2013 (CAGR increase +2.1% per year). Overall, the total number of adults aged 18+ in local authority funded day services has decreased steadily from financial year 2005 to 2006 to financial year 2012 to 2013 (CAGR decrease -1.7% per year).

Table 7.10 presents data on the gross current expenditure of local authorities and the unit costs of local authority funded day services for adults with learning disabilities aged under 65. Data for 2012 to 2013 is available for gross social services expenditure on day services and unit costs, but specific data for adults with learning disabilities aged 65 or over is not available (all adults aged 65 or over are placed in a single older people category).

When interpreting all expenditure tables, it is crucial to note that gross expenditure costs for 2011 to 2012 and 2012 to 2013 include costs transferred from the NHS to social services under VPN (for people with learning disabilities). The report 'Personal Social Services: Expenditure and Unit Costs England 2011-12 – Final Release' (<https://catalogue.ic.nhs.uk/publications/social-care/expenditure/pss-exp-eng-11-12-fin/pss-exp-eng-11-12-fin-rpt.pdf>) estimates that the funding transferred from the NHS to local authorities under VPN totalled £777 million. Furthermore, under a simultaneous NHS transfer scheme from PCTs to local authorities the report estimates that a further £95 million was transferred from the NHS to local authorities for services for adults with learning disabilities. However, these transfer figures cannot be broken down into specific categories of expenditure.

So, the recorded increase in gross expenditure for all services for adults with learning disabilities aged 18 to 64 from financial year 2010 to 2011 to financial year 2011 to 2012 of £872 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 (see Figure 7.2).

Table 7.10: local authority gross current expenditure (in millions) and unit costs of day services per week for adults with learning disabilities aged under 65

	Year								CAGR at constant prices 2005 to 2006 to 2012 to 2013
	2005 to 2006	2006 to 2007	2007 to 2008	2008 to 2009	2009 to 2010	2010 to 2011	2011 to 2012	2012 to 2013	
Gross social services expenditure on day services (,000s)	620.5	638.9	660.1	693.3	731.6	719.6	720.9	681.5	-0.2%
Unit cost of day services per week	284	303	298	324	na	364	358	333	+0.8%

Data source: NASCIS PSSEX (Personal social services expenditure data) Gross Current Expenditure and Unit Costs of Day Services

In 2012 to 2013 local authorities were spending over £681 million on day services for adults with learning disabilities aged 18 to 64 (including any transfers of funding from the NHS to local authorities, although this is likely to be a small figure for day services). This was, at an average unit cost of £333 per person per week (£17,316 per year). From 2005 to 2006 to 2012 to 2013, if inflation is taken into account, there was virtually no change in local authority expenditure on day services for adults with learning disabilities aged under 65 (CAGR decrease -0.2% per year). There was a steady increase from 2005 to 2006 to 2009 to 2010 and an absolute reduction between financial year 2009 to 2010 and financial year 2012 to 2013.

Taking inflation into account, the average unit cost of a day service place increased slightly from financial year 2005 to financial year 2006 to 2012 to 2013 (CAGR increase at constant prices +0.8% per year); there was a steady rise in unit costs of day services from financial year 2005 to 2006 to financial year 2010 to 2011 followed by an absolute reduction in unit costs from financial year 2010 to 2011 to financial year 2012 to 2013.

Other community services

Within the community social care services statistics, there are 2 major sources of data relating to other community services for adults with learning disabilities.

Table 7.11 presents data from Table P2F from the NASCIS RAP dataset. This is a consistent dataset up to 2012 to 2013 on the total number of adults with learning disabilities using a range of community services financially supported by local authorities. This includes information about equipment and adaptations, home care, meals, professional support and 'other' services. Data on overnight respite not in the person's home is not available beyond 2006 to 2007, and were not included in this table.

In 2012 to 2013 the most widely used of these local authority funded community services was home care. This was used by 42,200 adults with learning disabilities; the vast majority of whom (87.3%) were adults aged 18 to 64. From 2005 to 2006 to 2012 to 2013 there has been a steady increase in the number of people using home help (CAGR increase +6.8% per year). The 2005 to 2006 and 2006 to 2007 figures for home help included overnight respite in the person's home; therefore, these percentage change figures are an under-estimate of the actual increase in home help/home care for adults with learning disabilities.

In 2012 to 2013 the next most widely used of these local authority funded community services was professional support. 22,400 adults with learning disabilities used this support, the vast majority of whom (92.7%) were aged 18 to 64. Overall, from financial year 2005 to 2006 to financial year 2012 to 2013 there was a substantial decrease in the number of adults with learning disabilities receiving professional support in both age groups (CAGR decrease -7.3% per year). This general trend, however, conceals an increase of 5,625 people receiving professional support from financial year 2005 to 2006 to financial year 2008 to 2009 (CAGR increase +4.7%) followed by a sharp decrease of 18,070 people from financial year 2009 to 2010 to financial year 2012 to 2013 (CAGR decrease -17.9%).

Table 7.11: total number of adults with learning disabilities in England aged 18+ using other community services supported by local authorities

Adults with learning disabilities	Year								Compound annual growth rate 2005 to 2006 to 2012 to 2013
	2005 to 2006	2006 to 2007	2007 to 2008	2008 to 2009	2009 to 2010	2010 to 2011	2011 to 2012	2012 to 2013	
Equipment & adaptations									
Age 18 to 64	5,200	5,605	6,670	7,575	8,380	8,620	8,510	8,450	+7.2%
Age 65+	780	905	1,230	1,055	1,095	1,255	1,280	1,410	+8.8%
Total	5,980	6,515	7,900	8,630	9,475	9,875	9,790	9,860	+7.4%
Home care									
Age 18 to 64	23,865	26,250	29,275	33,315	33,515	35,580	35,245	36,855	+6.4%
Age 65+	2,805	3,365	4,120	4,130	4,355	4,740	4,960	5,345	+9.7%
Total	26,670	29,615	33,390	37,445	37,870	40,320	40,205	42,200	+6.8%
Meals									
Age 18 to 64	685	900	945	650	485	420	315	240	-13.9%
Age 65+	455	465	615	400	355	295	265	210	-10.5%
Total	1,140	1,365	1,560	1,050	840	715	580	450	-12.4%
Professional support									
Age 18 to 64	35,925	39,685	40,635	41,050	37,815	33,165	26,995	20,760	-7.5%
Age 65+	2,235	2,565	2,945	2,760	2,655	2,230	2,080	1,640	-4.3%
Total	38,155	42,245	43,580	43,810	40,470	35,395	29,075	22,400	-7.3%
Other									
Age 18 to 64	16,050	18,310	18,545	19,475	18,060	20,555	20,970	19,825	+3.1%
Age 65+	965	1,215	1,475	1,240	1,245	1,700	1,945	1,875	+10.0%
Total	17,020	19,525	20,015	20,715	19,310	22,255	22,920	21,700	+3.5%
Data source: NASCIS RAP (Referrals, Assessments and Packages of Care) Table P2F									

In 2012 to 2013 9,860 adults with learning disabilities received some form of equipment or adaptations, the vast majority of whom (85.7%) were adults aged 18 to 64. From 2005 to 2006 to 2010 to 2011 there was a sustained increase in the number of adults with learning disabilities receiving some form of equipment or adaptations in both age groups (CAGR increase +8.6% per year), with numbers being static from financial year 2010 to 2011 to financial year 2012 to 2013.

In 2012 to 2013 450 adults with learning disabilities received a meals service, over half of whom (53.3%) were aged 18 to 64. From financial year 2005 to 2006 to financial year 2012 to 2013, there was a sustained decrease in the number of adults with learning disabilities receiving meals services in both age groups (CAGR decrease -12.4% per year).

Finally, in 2012 to 2013 21,700 adults with learning disabilities received some other form of community-based service, the vast majority of whom (91.4%) were aged 18 to 64. From financial year 2005 to 2006 to financial year 2011 to 2012, there was a steady increase in the number of adults with learning disabilities receiving other community services in both age groups (CAGR increase +5.1% per year), with a 5.3% decrease from financial year 2011 to 2012 to financial year 2012 to 2013.

Table 7.12 presents data on the gross current expenditure of local authorities on other community services and the unit costs of local authority funded home care for adults with learning disabilities aged under 65. Specific data for adults with learning disabilities aged 65 or over is not available (all adults aged 65 or over are placed in a single older people category).

When interpreting all expenditure tables, it is crucial to note that gross expenditure costs for 2011 to 2012 include costs transferred from the NHS to social services under VPN (for people with learning disabilities). The report 'Personal Social Services: Expenditure and Unit Costs England 2011-12 – Final Release' (<https://catalogue.ic.nhs.uk/publications/social-care/expenditure/pss-exp-eng-11-12-fin/pss-exp-eng-11-12-fin-rpt.pdf>) estimates that the funding transferred from the NHS to local authorities under VPN totalled £777 million. Furthermore, under a simultaneous NHS transfer scheme from PCTs to local authorities the report estimates that a further £95 million was transferred from the NHS to local authorities for services for adults with learning disabilities, however, these transfer figures cannot be broken down into specific categories of expenditure.

In 2012 to 2013 local authorities were spending over £655 million on home care for adults with learning disabilities aged 18 to 64. This was at an average unit cost of £463 per person per week (£24,076 per year). Overall, from financial year 2005 to 2006 to financial year 2012 to 2013 there was a big increase in local authority expenditure on home care for adults with learning disabilities aged under 65 (CAGR at constant prices increase +10.8% per year), although there was slight drop in spending in absolute terms from financial year 2011 to 2012 to financial year 2012 to 2013. Taking into account inflation, the average unit cost of home care also increased from financial year 2005 to 2006 to financial year 2012 to 2013 (CAGR at constant prices increase +2.7% per year), although there was a drop in the absolute unit cost of home care from financial year 2010 to 2011 to financial year 2012 to 2013.

There is no specific data for local authority spending on professional support for adults with learning disabilities.

In 2012 to 2013 local authorities were spending over £144 million on other services for adults with learning disabilities aged 18 to 64. From financial year 2005 to 2006 to financial year 2011 to 2012, there was a sustained increase in local authority expenditure on other services for adults with learning disabilities aged under 65 (CAGR at constant prices increase +7.6% per year), although there was a substantial decrease of £24.5 million from financial year 2011 to 2012 to financial year 2012 to 2013.

In 2012 to 2013 local authorities were spending relatively small amounts on equipment and adaptations (£4.5 million) and meals services (£542,000) for adults with learning disabilities aged 18 to 64. From financial year 2005 to financial year 2006 to 2012 to 2013 there was overall a very big increase in local authority expenditure on equipment and adaptations for adults with learning disabilities aged under 65 (CAGR at constant prices increase +26% per year), however, this overall trend conceals an absolute reduction in expenditure of £2.3 million on equipment and adaptations from financial year 2009 to 2010 to financial year 2012 to 2013. For expenditure on meals, there was a sustained drop in expenditure on meals services from financial year 2005 to 2006 to financial year 2012 to 2013 (CAGR at constant prices decrease -13.2% per year).

Table 7.12: local authority gross current expenditure (in millions) and unit costs of other community services for adults with learning disabilities aged under 65

	Year								Compound annual growth rate at constant prices
	2005 to 2006	2006 to 2007	2007 to 2008	2008 to 2009	2009 to 2010	2010 to 2011	2011 to 2012	2012 to 2013	
Gross expenditure on equipment & adaptation	0.8	0.9	2.5	2.3	6.7	6.3	5.5	4.5	+26.0%
Gross expenditure on meals	1.3	1.0	0.9	1.2	0.8	0.7	0.6	0.5	-13.2%
Gross expenditure on other services	93.5	109.2	88.0	115.9	100.9	145.2	169.3	144.7	+4.8%
Gross expenditure on home care	288.1	349.1	390.0	464.8	488.9	557.1	658.7	655.5	+10.8%
Unit cost of home care per week	346	365	352	381	na	484	480	463	+2.7%
Data source: NASCIS PSSEX (Personal social services expenditure data) Gross Current Expenditure and Unit Costs of Other Community Services									

Social care assessment and review

There is a substantial amount of data available concerning social care assessment and processes for adults with learning disabilities in England, although with some changes over time (see previous reports).

Table 7.13 presents data from Tables A1, A7 and A11B from the NASCIS RAP dataset. Table A1 presents a consistent dataset up to financial year 2012 to 2013 on the number of existing adult clients with learning disabilities with completed reviews from 1 April to 31 March. Table A7 presents a consistent dataset up to financial year 2009 to 2010 on the time from first contact to completed assessment for new adult clients with learning disabilities. In the table below (Table 7.13?) the total number of adults with learning disabilities with completed assessments after first contact was used to provide an estimate of the number of new adult clients with learning disabilities receiving completed assessments from 1 April to 31 March. Table A11B provides this data directly from 2010 to 2011 onwards. Figures for new clients with learning disabilities with completed assessments do not seem to include adults with learning disabilities transferred from the NHS to local authorities under VPN.

In 2012 to 2013 there were 12,615 new adult clients with learning disabilities with completed local authority assessments, of whom 12.4% were aged 65 years or over. Overall, from financial year 2005 to 2006 to financial year 2012 to 2013 there was a substantial increase in the total number of new adult clients with learning disabilities with a completed assessment (CAGR increase +7.6% per year), however, this overall trend conceals notable variations. There was a substantial increase in the number of new adult clients with completed assessments from financial year 2005 to 2006 to financial year 2009 to 2010, with fluctuating numbers after that to 2012 to 2013 for both adults aged 18 to 64 and adults aged 65+.

In 2012 to 2013, there were 92,960 existing adult clients with learning disabilities with completed local authority reviews, 10.2% of whom were aged 65 years or over. Overall, from financial year 2005 to 2006 to financial year 2012 to 2013, there was a small increase in the number of existing adult clients with learning disabilities with completed reviews (CAGR increase +1.3% per year), with increases in both age categories (CAGR increase: age 18 to 64 +0.9% per year; age 65 or over +4.1% per year), however, this overall trend conceals a pattern of a substantial increase in the number of existing adult clients with completed reviews from financial year 2005 to 2006 to financial year 2009 to 2010. This was followed by a substantial drop from financial year 2009 to 2010 to financial year 2012 to 2013 (from 108,290 to 92,960; CAGR decrease -5% per year), with a much larger drop for working age adults than older adult existing clients with learning disabilities.

Table 7.13: number of new adult clients with learning disabilities with completed assessments and number of existing adult clients with learning disabilities with completed reviews 1 April to 31 March

	Year								Compound annual growth rate
	2005 to 2006	2006 to 2007	2007 to 2008	2008 to 2009	2009 to 2010	2010 to 2011	2011 to 2012	2012 to 2013	
New adult clients with learning disabilities with completed assessments									
Age 18 to 64	6,625	7,070	7,930	8,025	10,360	10,525	9,890	11,050	+7.6%
Age 65+	940	790	1,125	695	2,570	2,500	875	1,565	+7.6%
Total	7,560	7,860	9,055	8,720	12,930	13,025	10,765	12,615	+7.6%
Existing adult clients with learning disabilities with completed reviews									
Age 18 to 64	77,920	87,910	93,185	94,745	98,625	92,860	85,605	83,200	+0.9%
Age 65+	7,185	8,440	9,510	9,650	9,665	9,090	8,955	9,490	+4.1%
Total	85,105	96,350	102,695	104,400	108,290	101,950	94,565	92,960	+1.3%
Total adults with learning disabilities with completed assessments or reviews									
Age 18 to 64	84,545	94,980	101,115	102,770	108,985	103,385	95,495	94,250	+1.6%
Age 65+	8,125	9,230	10,635	10,345	12,235	11,590	9,830	11,055	+4.5%
Total	92,670	104,210	111,750	113,115	121,220	114,975	105,325	105,305	+1.8%
Data source: NASCIS RAP (Referrals, Assessments and Packages of Care) Table A1, Table A7, Table A11B									

Table 7.14 presents data on the gross current expenditure of local authorities on the assessment and care management of adults with learning disabilities aged under 65. Specific data for adults with learning disabilities aged 65 or over is not available (all adults aged 65 or over are placed in a single older people category).

When interpreting all expenditure tables, it is crucial to note that gross expenditure costs for 2011 to 2012 include costs transferred from the NHS to social services under VPN (for people with learning disabilities). The report 'Personal Social Services: Expenditure and Unit Costs England 2011-12 – Final Release' (<https://catalogue.ic.nhs.uk/publications/social-care/expenditure/pss-exp-eng-11-12-fin/pss-exp-eng-11-12-fin-rpt.pdf>) estimates that the funding transferred from the NHS to local authorities under VPN totalled £777 million. Furthermore, under a simultaneous NHS transfer scheme from PCTs to local authorities the report states that a further £95 million was transferred from the NHS to local authorities for services for adults with learning disabilities. However, these transfer figures cannot be broken down into specific categories of expenditure.

In 2012 to 2013, local authorities were spending over £292 million on assessment and care management for adults with learning disabilities aged 18 to 64.

Taking inflation into account, from 2005 to 2006 to 2012 to 2013 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 +3.6% per year), with some fluctuations over time.

Table 7.14: local authority gross current expenditure on assessment and care management for adults with learning disabilities aged under 65 (in millions)

	Year								Compound annual growth rate at constant prices 2005 to 2006 to 2012 to 2013
	2005 to 2006	2006 to 2007	2007 to 2008	2008 to 2009	2009 to 2010	2010 to 2011	2011 to 2012	2012 to 2013	
Gross social services expenditure on assessment and care management	205.4	201.3	199.8	254.5	269.2	247.0	291.4	292.6	+3.6%

Data source: NASCIS PSSEX (Personal social services expenditure data) Gross Current Expenditure on Assessment and Care Management

Direct payments and self-directed support

Although direct payments and self-directed support for adults with learning disabilities are a fast-developing policy area, an increasing amount of data is becoming available.

The RAP system included a new indicator in 2009 to 2010 on the number of adults using direct payments and/or self-directed support funded by councils with social services responsibilities. While direct payments can be provided without other elements of self-directed support (such as support planning), self-directed support can be provided either through direct payments or through other delivery mechanisms (such as brokered personal budgets or personal budgets administered by local authorities). This data is now available for financial year 2009 to 2010 through to financial year 2012 to 2013 (see Table 7.15). These figures are also represented graphically in Figure 7.3 below).

Table 7.15 shows that 78,820 adults with learning disabilities in 2012 to 2013 were reported by local authorities to be making use of a direct payment and/or self-directed support; 3,590 adults used a direct payment and 75,230 adults used some form of self-directed support (the numbers are those reported in RAP Table SD1).

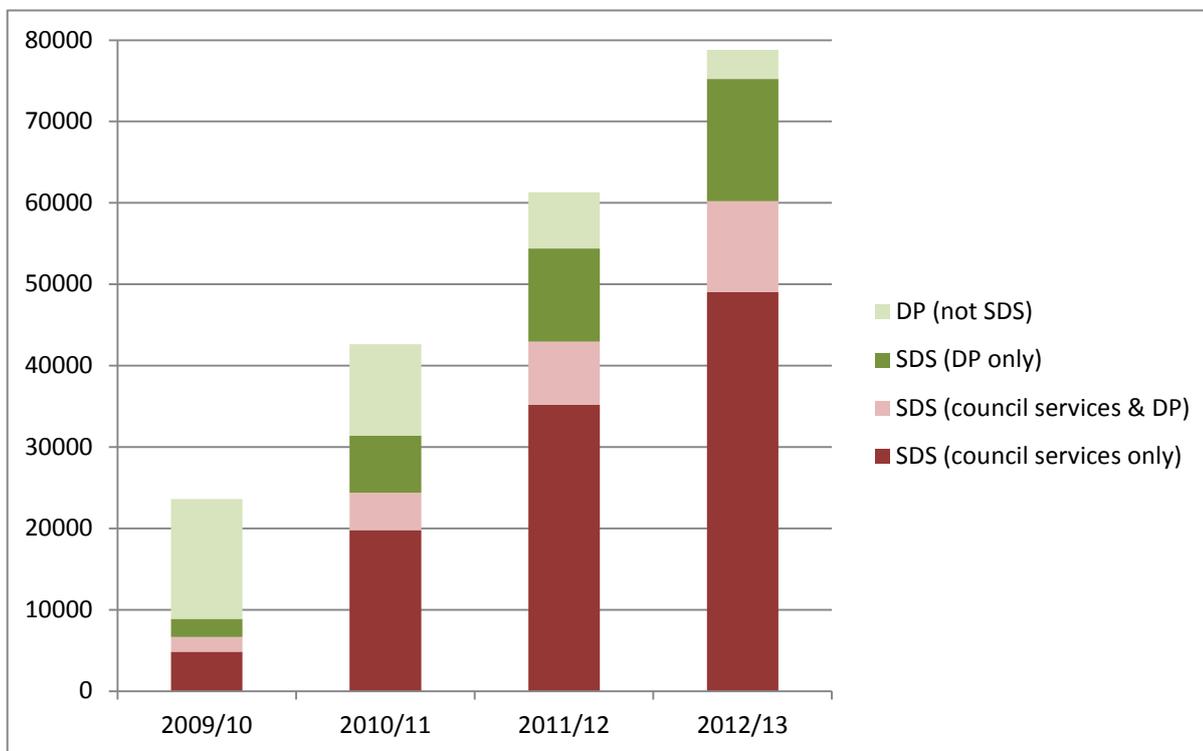
These figures were a substantial change from 2009 to 2010. First, there was a big overall increase in the total number of adults making usage of either a direct payment or self-directed support (CAGR increase +49.5%). Within this overall increase, however, there were changes in the patterns of reported usage of direct payments and self-directed support. This may reflect changes in council reporting as well as changes in usage of self-directed support.

Table 7.15: Number of adults with learning disabilities in England using direct payments and self-directed support, supported by local authorities

Type of direct payment/self-directed support	Year				Compound annual growth rate 2009 to 2010 to 2012 to 2013
	2009 to 2010	2010 to 2011	2011 to 2012	2012 to 2013	
Direct Payment (not self-directed support)	14,705	11,205	6,910	3,590	-37.5%
Self-Directed Support:					
Direct payment only	2,235	7,050	11,470	15,010	+88.7%
Council services only	4,870	19,790	35,190	49,035	+115.9%
Both direct payments and council services	1,795	4,580	7,745	11,185	+84.0%
Self-directed support total	8,900	31,535	54,405	75,230	+103.7%
Total Direct Payments and Self-Directed Support	23,605	42,625	61,320	78,820	+49.5%

Data source: NASCIS RAP (Referrals, Assessments and Packages of Care) Table SD1

Figure 7.3: number of working age adults with learning disabilities getting a direct payment (DP) / self-directed support (SDS)



For example, the number of adults reported to be using self-directed support in the form of direct payments only increased from financial year 2009 to 2010 to financial year 2012 to 2013, however, the number of adults reported as using direct payments (not self-directed support) decreased from financial year 2009 to 2010 to financial year 2012 to 2013. Overall, the number

of adults using either direct payment only (not self-directed support) or direct payment only (as part of self-directed support) only increased modestly from financial year 2009 to 2010 to financial year 2012 to 2013 (16,940 people to 18,600 people; CAGR increase +3.2% per year).

The biggest increase in usage of self-directed support from financial year 2009 to 2010 to financial year 2012 to 2013 was in ‘council services only’ self-directed support – often termed ‘managed budgets’. There are currently questions about the extent to which these forms of self-directed support represent a change from ‘traditional’ models of council service usage.

Table 7.16 presents data on the gross current expenditure of local authorities and the unit costs of local authority funded direct payments for adults with learning disabilities aged under 65. Specific data for adults with learning disabilities aged 65 or over is not available (all adults aged 65 or over are placed in a single older people category).

When interpreting all expenditure tables, it is crucial to note that gross expenditure costs for 2011 to 2012 onwards include costs transferred from the NHS to social services under VPN (for people with learning disabilities). The report ‘Personal Social Services: Expenditure and Unit Costs England 2011-12 – Final Release’ (<https://catalogue.ic.nhs.uk/publications/social-care/expenditure/pss-exp-eng-11-12-fin/pss-exp-eng-11-12-fin-rpt.pdf>) estimates that the funding transferred from the NHS to local authorities under VPN totalled £777 million. Furthermore, under a simultaneous NHS transfer scheme from PCTs to local authorities the report estimates/states that a further £95 million was transferred from the NHS to local authorities for services for adults with learning disabilities, however, these transfer figures cannot be broken down into specific categories of expenditure.

Table 7.16: local authority gross current expenditure and unit costs of direct payments for adults with learning disabilities aged under 65 (in millions)									
	Year								Compound annual growth rate at constant prices 2005 to 2006 to 2012 to 2013
	2005 to 2006	2006 to 2007	2007 to 2008	2008 to 2009	2009 to 2010	2010 to 2011	2011 to 2012	2012 to 2013	
Gross social services expenditure on direct payments	42.2	60.8	87.2	132.4	198.3	260.2	324.4	385.0	+35.1%
Unit cost of direct payments per week	179	196	191	222	na	230	270	276	+4.8%

Data source: NASCIS PSSEX (Personal social services expenditure data) Gross Current Expenditure and Unit Costs of Direct Payments

In 2012 to 2013, local authorities were spending £385 million on direct payments for adults with learning disabilities aged 18 to 64, at an average unit cost of £276 per person per week (£14,352 per year).

From financial year 2005 to 2006 to financial year 2012 to 2013, there was a sustained, substantial increase in local authority expenditure on direct payment for adults with learning disabilities aged under 65 (CAGR increase at constant prices +35.1% per year). The average

unit cost of a direct payment increased much less rapidly from financial year 2005 to 2006 to financial year 2012 to 2013 (CAGR at constant prices +4.8% per year).

Service user experiences of social care

For financial year 2011 to 2012 and financial year 2012 to 2013, the Health and Social Care Information Centre conducted a national survey of adult users of personal social services ('The Personal Social Services Adult Social Care Survey, England 2012-13 (Final Release)' – see <http://www.hscic.gov.uk/catalogue/PUB12631>). This was to investigate various aspects of adults' experiences of adult social care. From January to March 2013, a stratified random sample of adults fitting the RAP definition of 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.

Table 7.17 below reports selected findings from the survey for 2011 to 2012 and 2012 to 2013 for adults with learning disabilities, adults with physical disabilities and adults with mental health difficulties. Where data is available for 2011 to 2012 and 2012 to 2013 it shows remarkable consistency across the 2 years of data collection.

As Table 7.17 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 on all indicators in Table 7.17 (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.

Reasons for these differences between adults with learning disabilities and other client groups may include:

- direct payments and personal budgets for adults with learning disabilities
- service user experiences of social care
- differences in experiences of social care services and self-perceptions of health
- demographic differences between adults with learning disabilities and some other client groups (for example respondents with learning disabilities were much more likely to be under 65 than respondents with physical disabilities, which could have an impact on self-reported general health)
- differences between easy-read and standard versions of some questions (for example the quality of life and satisfaction questions), with different numbers of response options and different wordings of the options
- differences in how the survey was completed, with respondents with learning disabilities much less likely to have completed the survey by themselves and much more likely to have completed the survey with help from others (particularly care workers) than other groups

Table 7.17: Adult service user experiences of social care 2011 to 2012 and 2012 to 2013						
Survey Findings	Learning Disabilities		Physical Disabilities		Mental Health	
	2011 to 2012	2012 to 2013	2011 to 2012	2012 to 2013	2011 to 2012	2012 to 2013
Methodological issues						
Number of survey respondents	10,575	12,060	42,455	46,510	9,075	9,320
% completed survey by themselves	9%	8%	33%	32%	37%	33%
% completed survey with help from...						
A care worker	51%	52%	12%	13%	21%	24%
Someone living in household	25%	26%	19%	20%	16%	16%
Someone living outside household	15%	15%	35%	36%	26%	28%
% had help from...						
Didn't have help		7%		30%		31%
Someone else read Qs to me		63%		40%		39%
Someone else translated Qs for me		62%		9%		10%
Someone else wrote down answers for me		48%		37%		28%
Talked through Qs with someone else		28%		29%		26%
Someone answered for me without asking me the Qs		9%		8%		11%
Quality of life						
Quality of life is...						
So good it could not be better/very good	40%	40%	25%	26%	28%	30%
Good	41%	41%	30%	30%	28%	28%
Alright	17%	17%	34%	33%	31%	30%
Bad	1%	1%	7%	7%	8%	7%
So bad it could not be worse/very bad	1%	1%	4%	4%	5%	5%
Satisfaction with services						
Extremely/very satisfied	72%	75%	62%	62%	61%	62%
Quite satisfied	20%	18%	29%	28%	26%	26%
Neither satisfied nor dissatisfied	6%	5%	6%	6%	8%	7%
Quite dissatisfied	1%	1%	2%	2%	3%	2%
Extremely/very dissatisfied	0%	1%	2%	2%	3%	3%
The way I am helped and treated...						
Makes me think/feel better about myself	76%	77%	56%	56%	58%	60%
Does not affect way I think/feel	21%	20%	34%	34%	31%	29%
Sometimes undermines way I think/feel	3%	3%	9%	9%	9%	9%
Completely undermines way I think/feel	0%	1%	1%	1%	2%	2%
General health						
Very good	39%	40%	6%	6%	11%	11%
Good	31%	32%	23%	25%	30%	29%
Fair	23%	21%	48%	47%	40%	40%
Bad	6%	6%	16%	16%	14%	15%
Very bad	1%	1%	6%	6%	5%	5%
Health state today – pain or discomfort						
No pain or discomfort		63%		22%		40%
Moderate pain or discomfort		32%		59%		49%
Extreme pain or discomfort		5%		19%		11%
Health state today – anxiety or depression						
Not anxious or depressed		49%		48%		36%
Moderately anxious or depressed		48%		45%		47%
Extremely anxious or depressed		3%		7%		17%
Data source: Health and Social Care Information Centre: Personal Social Services Adult Social Care Survey						

8. Employment

Summary

The Health and Social Care Information Centre reports data from local authority returns on the employment of 18 to 64 year-old adults with learning disabilities.

- in 2012 to 2013 7% of working age adults with learning disabilities (9,845 people) were reported to be in some form of paid or self-employment
- most people (70.3%) in paid/self-employment worked for less than 16 hours per week
- men were more likely to be in paid/self-employment than women (men 64% of adults with learning disabilities in paid/self-employment), and were more likely to be working 30+ hours per week than women (men 79.5% of those working 30+ hours per week)
- employment rates varied considerably across local authorities, ranging from 0% to 20.4% of working age adults with learning disabilities known to local authorities
- an additional 9,245 working age adults with learning disabilities were engaged in unpaid voluntary work only

Employment

The National Adult Social Care Intelligence Service (NASCIS) provides figures 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, with some data available on voluntary (unpaid) employment at the time of their latest assessment or review. The figures run from April to March.

As Table 8.1 shows, from financial year 2008 to 2009 to financial year 2012 to 2013 the number of working age adults with learning disabilities in paid/self employment has increased substantially from financial year 2008 to 2009 to financial year 2012 to 2013 (CAGR overall +21.9%). The number of working age adults engaged in voluntary (unpaid) employment also increased substantially over the same time period (+19.2%). However, the bulk of the apparent increase occurred from financial year 2008 to 2009 to financial year 2009 to 2010, and may largely be an artefact of local authorities improving their data collection for this newly introduced indicator.

The vast majority (89%) of people with learning disabilities who worked regularly in paid/self employment were working part-time hours of less than 30 hours a week.

From a peak in 2009 to 2010, the number and percentage of working age adults with learning disabilities working 30+ hours a week has decreased year on year to 2012 to 2013.

Rates of paid/self employment differ between men and women, particularly in relation to the numbers working 30+ hours per week. Of those in paid/self employment, 64% were men; and of those working 30+ hours per week, 79.5% were men.

Table 8.1: Number of Adults with Learning Disabilities Known to Local Authorities in Employment 2008/09 – 2012 to 2013						
Type of work	2008 to 2009	2009 to 2010	2010 to 2011	2011 to 2012	2012 to 2013	Compound annual growth rate 2008 to 2009 to 2012 to 2013
Paid or self employed						
30+ hrs per week	700	1300	1295	1185	1075	+11.3%
16 to 29 hrs per week	860	1720	1825	1840	1845	+21.0%
4 to 15 hrs per week	1390	2925	3020	3490	3565	+26.6%
0 to 3 hrs per week	1330	2395	2570	2810	2730	+19.7%
Working regularly but less than weekly	190	425	495	585	630	+34.9%
TOTAL paid/self employment	4465	8765	9210	9905	9845	+21.9%
Voluntary (unpaid) work						
Vol work and paid/self employment	645	1115	995	1050	1190	+16.6%
Vol work only	4580	8275	7615	8675	9245	+19.2%
Data source: ASC-CAR L1						

Over this time period, councils have also reported increases in the number of working age adults with learning disabilities known to them. Table 8.2 shows the percentage of working age adults with learning disabilities known to local authorities who were in paid/self employment, also broken down by Government Office region. Table 8.2 shows that the proportion of working age adults with learning disabilities in any level of paid/self employment remained relatively stable, at 7% in 2012 to 2013, with a CAGR annual growth rate of 0.7% over this time period.

The overall paid/self employment rates for financial year 2008 to 2009 to financial year 2012 to 2013 are also presented regionally in Table 8.2. Reported employment rates varied by local authority from 0% in Sandwell to 23% in Rutland. If the highest and lowest performing local authorities are excluded, reported employment rates varied from 0.8% to 17% (a 22-fold variation).

Table 8.2: percentage of Adults with Learning Disabilities Known to Local Authorities in Employment between 2008 to 2009 and 2012 to 2013

Government office region	2008 to 2009	2009 to 2010	2010 to 2011	2011 to 2012	2012 to 2013	Compound annual growth rate 2008 to 2009 to 2012 to 2013
North East	5.9	4.8	5.7	5.7	5.5	-1.7%
North West	5.2	5.3	4.9	5.4	5.5	+1.4%
Yorkshire and the Humber	6.3	5.3	6.3	6.8	6.6	+1.2%
East Midlands	5.4	6.0	5.3	5.8	5.2	-0.9%
West Midlands	2.9	4.1	5.5	6.3	5.6	+18.0%
South West	6.7	5.7	5.7	5.8	7.2	+1.8%
Eastern	5.9	6.2	6.0	7.2	6.5	+2.5%
London	9.8	8.5	8.6	9.3	9.1	-1.8%
South East	10.2	9.6	9.6	9.6	9.7	-1.0%
England	6.8	6.4	6.6	7.1	7.0	+0.7%
Data source: ASC-CAR L1; NI 146; ASCOF 1E						

9. Abuse of vulnerable adults

Summary

The Health and Social Care Information Centre report returns by local authorities on the number of vulnerable adults referred due to concerns about possible abuse:

- in 2012 to 2013 there were 20,660 referrals concerning adults with learning disabilities, 92% of which concerned adults aged 18 to 64 years (for other groups of vulnerable adults only 26% concern adults with 18 to 64)
- the number of referrals concerning adults with learning disabilities increased by 13% from financial year 2010 to 2011 to financial year 2011 to 2012, but then decreased by 6% from financial year 2011 to 2012 to financial year 2012 to 2013. In contrast, the number of referrals concerning other groups of vulnerable adults increased consistently, by 14% from financial year 2010 to 2011 to financial year 2011 to 2012, and again by 3% from financial year 2011 to 2012 to financial year 2012 to 2013
- for adults with learning disabilities, numbers of repeat referrals rose from 4,145 in 2010 to 2011 (21.3% of learning disabilities referrals) to 5,215 in 2012 to 2013 (25.2% of learning disabilities referrals)
- of the 15,305 reported completed referrals concerning adults with learning disabilities aged 18 to 64 years (data broken down by client group for adults aged 65 or more is not available) in 2012 to 2013, allegations of abuse were substantiated in over a third of cases (35.3%) and not substantiated in just over a quarter of cases (27.1%), with the outcome of just over a further quarter of cases (26.4%) reported as not determined/inconclusive
- for adults with learning disabilities aged 18 to 64 years, the most common type of alleged abuse was physical abuse (36%), followed by neglect (18.8%), emotional/psychological abuse (17.9%), financial abuse (13.2%) and sexual abuse (9.2%)
- for adults with learning disabilities aged 18 to 64 years in 2012 to 2013 the most common alleged perpetrator was a member of social care staff (29.6%), followed by another vulnerable adult (20.6%), another family member (excluding partners, 14.2%) and the perpetrator not being known (11.2%). From financial year 2010 to 2011 to financial year 2012 to 2013, there was a decrease of 5.9% in the proportion of alleged perpetrators being identified as social care workers
- for adults with learning disabilities aged 18 to 64 years in 2012 to 2013 over half of all referrals were made by social care staff (55.6%); the next most common source of referrals were health staff (11%) followed by a diverse range of referral sources

Introduction

For the first time in 2010 to 2011 all local authorities with social services responsibilities were mandated to return experimental statistics concerning the number of vulnerable people aged 18 or over who they had been made aware of with regards to potential abuse. This data collection was repeated in financial years 2011 to 2012 and 2012 to 2013.

<http://www.hscic.gov.uk/article/2021/Website-Search?productid=14155&q=abuse+of+vulnerable+adults&sort=Relevance&size=10&page=1&area=both#top>. The data includes:

- the number of ‘alerts’ received by local authorities (although not all local authorities record data on alerts and only begin to record and return data at the referral stage). Due to the incompleteness of data and other data quality issues, data on alerts is not available for 2012 to 2013 and has not been included in this report, although data for earlier years is available in earlier ‘People with Learning Disabilities in England’ reports
- the number of referrals for safeguarding investigations to be conducted by local authorities, including data on the source of the referral (social care staff; health staff; self-referral; family member; friend/neighbour; other service user; Care Quality Commission (CQC); housing; education/training/workplace establishment; police; other)
- the number of completed referrals in terms of completion of safeguarding investigations, including:
 - data on the conclusion of these completed referrals (substantiated; partly substantiated; not substantiated; not determined/inconclusive)
 - data on the outcomes of completed referrals. Complete data is only available for 2010 to 2011 and 2011 to 2012 (criminal prosecution/formal caution; police action; community care assessment; removal from property or service; management of access to the vulnerable adult; referred to the protection of vulnerable adults (PoVA) list/ISA; referral to registration body; disciplinary action; action by the CQC; continued monitoring; counselling/training/treatment; referral to court mandated treatment; referral to multi-agency public protection arrangements (MAPPA); action under Mental Health Act; action by contract compliance; exoneration; no further action; not known)
 - data on the nature of the alleged abuse – these categories are not mutually exclusive (physical; sexual; emotional/psychological; financial; neglect; discriminatory; institutional)
 - data on the relationship of the alleged perpetrator to the vulnerable adult (partner; other family member; healthcare worker; volunteer/befriender; social care staff; other professional; other vulnerable adult; neighbour/friend; stranger; not known; other)

Table 9.1 below presents data on the number of referrals, repeat referrals and completed referrals reported by local authorities from financial year 2010 to 2011 to financial year 2012 to 2013, broken down by age band, sex (where the data is available), and adults with learning disabilities compared with all other groups of vulnerable adults.

As Table 9.1 shows, councils reported 20,660 referrals concerning adults with learning disabilities in 2012 to 2013; 19.1% of the total number of referrals recorded by local authorities. The pattern of referrals concerning adults with learning disabilities is quite different to that for other groups of vulnerable adults. The majority of referrals for adults with learning disabilities concern adults aged 18 to 64 years (91.7%), whereas for other vulnerable groups the majority of referrals concerns adults aged 65 years or more (74.4%). Indeed, for adults aged 18 to 64 years, referrals concerning people with learning disabilities constitute almost half of all referrals

in this age group (45.9%). Also in this younger age group, for adults with learning disabilities more referrals were reported concerning men than women (54.9% men), in contrast to the pattern of referrals for other vulnerable adults aged 18 to 64 years (43.7% men).

The number of referrals concerning adults with learning disabilities increased by 12.9% from financial year 2010 to 2011 to financial year 2011 to 2012, but then decreased by 6% from financial year 2011 to 2012 to financial year 2012 to 2013. In contrast, the number of referrals concerning other groups of vulnerable adults increased consistently over this time period, by 13.9% from 2010 to 2011 to 2011 to 2012, and again by 2.6% from financial year 2011 to 2012 to financial year 2012 to 2013.

For adults with learning disabilities and other vulnerable groups of adults, the number of referrals that were repeat referrals rose consistently over this time period. For adults with learning disabilities, numbers of repeat referrals rose from 4,145 in 2010 to 2011 (21.3% of learning disabilities referrals) to 5,215 in 2012 to 2013 (25.2% of learning disabilities referrals). For other groups of vulnerable adults, numbers of repeat referrals rose from 9,770 in 2010 to 2011 (13.1% of other vulnerable adult referrals) to 12,130 in 2012 to 2013 (13.9% of other vulnerable adult referrals). It is clear that the proportion of repeat referrals is much higher and increasing over time for adults with learning disabilities, whereas it is lower and remaining stable for other groups of vulnerable adults.

Finally, Table 9.1 shows the number of completed referrals from financial year 2010 to 2011 to financial year 2012 to 2013. As with the total number of referrals, the number of completed referrals increased for adults with learning disabilities by 10.6% from financial year 2010 to 2011 to financial year 2011 to 2012, then decreased by 2.6% from financial year 2011 to 2012 to financial year 2012 to 2013. For other groups of vulnerable adults, the numbers of completed referrals increased steadily throughout this time period, by 13.9% from financial year 2010 to 2011 to financial year 2011 to 2012, and again by 3.5% from financial year 2011 to 2012 to financial year 2012 to 2013.

Table 9.1: abuse of vulnerable adults (AVA) statistics 2010 to 2011 to 2012 to 2013: number of AVA referrals, repeat referrals and completed referrals (AVA Table 1)									
	Referrals			Repeat Referrals			Completed Referrals		
	2010 to 2011	2011 to 2012	2012 to 2013	2010 to 2011	2011 to 2012	2012 to 2013	2010 to 2011	2011 to 2012	2012 to 2013
Aged 18 to 64									
Learning disabilities									
female	8,630	9,480	8,840	1,945	2,315	2,390	6,915	7,450	7,195
male	9,380	10,730	10,095	1,940	2,435	2,495	7,445	8,150	8,110
total	18,005	20,205	18,935	3,885	4,750	4,885	14,360	15,595	15,305
All other groups									
female									
male	11,005	12,380	12,550	1,460	1,750	2,215	8,160	9,555	9,800
total	8,225	9,555	9,745	1,115	1,290	1,665	6,190	7,440	7,565
	19,230	21,935	22,295	2,575	3,040	3,880	14,350	16,995	17,365
Aged 65+									
Learning disabilities									
female	755	910	880	145	175	185	595	795	690
male	695	865	845	115	135	145	555	710	670
total	1,450	1,775	1,725	260	310	330	1,150	1,505	1,360
All other groups									
female									
male	38,180	42,165	43,690	4,965	6,035	6,850	31,110	34,525	35,825
total	17,810	20,950	20,995	2,230	2,635	3,065	14,105	16,300	17,030
	55,990	63,115	64,955	7,195	8,670	9,915	45,215	50,825	52,855
Total aged 18+									
Learning disabilities									
female	9,385	10,390	9,720	2,090	2,490	2,575	7,485	8,245	7,885
male	10,075	11,595	10,940	2,055	2,570	2,640	7,985	8,860	8,780
total	19,460	21,985	20,660	4,145	5,060	5,215	15,470	17,105	16,665
All other groups									
female									
male	48,670	54,545	56,510	6,425	7,785	9,065	39,270	44,080	45,625
total	25,995	30,505	30,740	3,345	3,925	4,730	20,295	23,740	24,595
	74,665	85,050	87,250	9,770	11,710	12,130	59,565	67,820	70,220

Data source: AVA Table 1

Table 9.2 shows the case conclusion status for completed referrals from financial year 2010 to 2011 to financial year 2012 to 2013 (AVA Table 7). Of the 15,305 reported completed referrals concerning adults with learning disabilities aged 18 to 64 years (data broken down by client group for adults aged 65 or more is not available) in 2012 to 2013, the allegations of abuse were substantiated in over a third of cases (35.3%) and not substantiated in just over a quarter of cases (27.1%), with the outcome of just over a further quarter of cases (26.4%) reported as not determined/inconclusive (data on 'Partly substantiated' cases was not provided for 2012 to 2013).

This compares with the data for other vulnerable groups aged 18 to 64 years, where 28.5% of allegations were substantiated, 28.5% were not substantiated and 30.8% were not determined/inconclusive.

For adults with learning disabilities aged 18 to 64, there have been increases from 2010 to 2011 to 2012 to 2013 in the number of substantiated (Compound Annual Growth Rate annual increase +2.3%), not substantiated (CAGR +5.2%) and not determined/inconclusive (CAGR +4.3%) cases.

Table 9.2: AVA statistics 2010 to 2011 to 2012 to 2013: case conclusion status for completed referrals (AVA Table 7)¹¹

	Substantiated			Partly substantiated			Not substantiated			Not determined/ Inconclusive		
	2010 to 2011	2011 to 2012	2012 to 2013	2010 to 2011	2011 to 2012	2012 to 2013	2010 to 2011	2011 to 2012	2012 to 2013	2010 to 2011	2011 to 2012	2012 to 2013
Aged 18 to 64 ^a												
Learning disabilities total	5170	5430	5415	1230	1575	no data ^b	3750	4055	4150	3720	4275	4045
Other total	4050	4715	4955	1445	1845	no data ^b	4455	5070	4950	4415	5210	5355
Data source: AVA Table 7												

- a) Data only broken down by client type for adults aged 18 to 64
- b) No data for 'Partly substantiated' cases provided for 2012 to 2013

Table 9.3 shows the number of referrals concerning allegations of abuse broken down by the nature of the alleged abuse (this data is only broken down by client type for adults aged 18 to 64 years). These categories are not mutually exclusive as allegations concerning multiple forms of abuse can be made (although data on the number of referrals which involved multiple types of abuse is only provided for 2010 to 2011).

As Table 9.3 shows, for adults with learning disabilities aged 18 to 64 years, the most common type of alleged abuse was physical abuse (36%), followed by neglect (18.8%), emotional/psychological abuse (17.9%), financial abuse (13.2%) and sexual abuse (9.2%). Allegations of institutional abuse (3.7%) and discriminatory abuse (2.6%) were less common for adults with learning disabilities aged 18 to 64 years. These proportions are broadly similar to those reported for 2010 to 2011.

Compared with other groups of vulnerable adults aged 18 to 64 in 2012 to 2013, allegations of physical abuse and neglect were more likely to be made concerning people with learning disabilities, whereas allegations of financial abuse were less likely to be made concerning people with learning disabilities.

¹¹ Data only broken down by client type for adults aged 18 to 64

Table 9.3: AVA statistics 2010 to 2011 to 2012 to 2013: nature of alleged abuse (AVA Table 4b)

	Nature of alleged abuse								Total
	Physical	Sex-ual	Emotional/ psychological	Financial	Neglect	Discriminatory	Institutional	N. unique referrals which involved multiple types of abuse	
Aged 18 to 64									
Learning Disabilities									
2010 to 2011	8,305	2,350	3,625	2,885	3,480	280	620	3,350	21,960
2011 to 2012	9,695	2,415	4,560	3,340	4,510	315	960	no data	25,800
2012 to 2013	8,665	2,210	4,315	3,165	4,535	285	890	no data	24,065
All Other Groups									
2010 to 2011	7,255	2,230	5,645	5,480	3,375	315	500	4,725	24,800
2011 to 2012	8,625	2,725	6,765	6,110	4,140	380	620	no data	29,360
2012 to 2013	8,680	2,635	6,755	6,095	4,480	385	760	no data	29,790
Total									
2010 to 2011	15,560	4,580	9,270	8,365	6,855	595	1,120	8,075	46,760
2011 to 2012	18,320	5,140	11,325	9,450	8,650	695	1,580	no data	55,160
2012 to 2013	17,345	4,845	11,070	9,260	9,015	670	1,650	no data	53,855
Data source: AVA Table 4b									

Table 9.4 shows the number of referrals concerning allegations of abuse broken down by the relationship of the alleged abuser to the vulnerable adult (this data is only broken down by client type for adults aged 18 to 64 years) for financial year 2010 to 2011 to financial year 2012 to 2013.

As Table 9.4 shows, for adults with learning disabilities aged 18 to 64 years in 2012 to 2013 the most common alleged perpetrator was a member of social care staff (29.6%): this overall figure breaks down into 15% residential care staff; 6.9% domiciliary care staff; 1.8% day care

staff; 0.8% social worker/care manager; 0.6% self-directed support staff; and 4.1% other social care staff. The next most common alleged perpetrator was another vulnerable adult (20.6%), another family member (excluding partners, 14.2%) and the perpetrator not being known (11.2%). Less commonly reported alleged perpetrators included 'other' (7.5%), a neighbour/friend (6.4%), a partner (3.5%), a healthcare worker (2.5%), a stranger (2.3%), another professional (1.9%) and a volunteer/befriender (0.2%). From financial year 2010 to 2011 to financial year 2012 to 2013, there was a decrease of 5.9% in the proportion of alleged perpetrators being identified as social care workers.

Compared with other vulnerable adults, a greater proportion of alleged perpetrators concerning adults with learning disabilities aged 18 to 64 were social care workers (29.6% LD vs 17.8% non-LD) and other vulnerable adults (20.6% LD vs 11.3% non-LD), and a smaller proportion were a partner of the vulnerable adult (3.5% LD vs 12.3% non-LD).

Table 9.4: AVA statistics 2010 to 2011 to 2012 to 2013: relationship of alleged perpetrator to vulnerable adult (Table 6b)

Relationship of alleged perpetrator to vulnerable adult											
	Partner	Other family member	Healthcare worker	Volunteer/befriender	Social care staff	Other professional	Other vulnerable adult	Neighbour/friend	Stranger	Not known	Other
Aged 18 to 64											
Learning Disabilities											
2010 to 2011	670	2,715	360	60	4,335	465	3,990	1,220	435	2,515	1,530
2011 to 2012	565	2,820	655	50	5,865	585	4,445	1,170	470	2,470	1,640
2012 to 2013	685	2,750	490	35	5,735	360	3,995	1,245	445	2,165	1,450
All Other Groups											
2010 to 2011	2,465	3,625	600	75	2,690	500	2,060	2,115	515	2,950	1,935
2011 to 2012	2,725	3,945	1,080	60	3,580	770	2,295	2,385	655	3,010	2,570
2012 to 2013	2,820	3,990	1,055	60	4,060	470	2,495	2,270	660	2,865	2,120
Total											
2010 to 2011	3,135	6,340	960	135	7,025	965	6,050	3,335	950	5,465	3,465
2011 to 2012	3,290	6,765	1,735	110	9,445	1,355	6,740	3,555	1,125	5,480	4,210
2012 to 2013	3,505	6,740	1,545	95	9,795	830	6,490	3,515	1,105	5,030	3,570
Data source: AVA Table 6b											

Table 9.5 shows the number of referrals concerning allegations of abuse broken down by the source of referral (this data is only broken down by client type for adults aged 18 to 64 years) for financial year 2010 to 2011 to financial year 2012 to 2013.

As Table 9.5 shows, for adults with learning disabilities aged 18 to 64 years in 2012 to 2013 over half of all referrals were made by social care staff (55.6%): this overall figure breaks down into 21.1% residential care staff; 10.8% social workers/care managers; 8.6% domiciliary care staff; 6.1% day care staff; 0.8% self-directed support staff; and 8.7% 'other' social care staff.

The next most common source of referrals was health staff (11%): this overall figure breaks down into 5.2% primary care/community health staff; 3.6% secondary care staff; and 2.1% mental health staff.

Other sources of referrals for adults with learning disabilities aged 18 to 64 years were diverse, including 'other' sources of referral (18% of referrals), family members of the vulnerable adult (4.2%), the police (3.8%), referrals from housing (2.5%), self-referrals (1.9%), referrals from education/training/workplaces (1.9%) and referrals from the CQC (1.1%). These proportions are broadly similar to those reported for 2010 to 2011.

Compared with other groups of vulnerable adults aged 18 to 64 in 2012 to 2013, a greater proportion of referrals concerning people with learning disabilities came from social care staff (55.6% vs 30.9% non-LD) and a smaller proportion came from health staff (11% LD vs 30.9% non-LD).

Table 9.5: Abuse of Vulnerable Adults (AVA) statistics 2010 to 2011 and 2011 to 2012.

Source of referral (AVA Table 3)

	Source of referral										
	Social care staff	Health staff	Self-referral	Family member	Friend/ neighbour	Other service user	CQC	Housing	Education / training/ workplace	Police	Other
Aged 18 to 64											
Learning Disabilities											
2010 to 2011	9,970	1,740	570	795	160	50	120	490	390	655	3,060
2011 to 2012	11,350	2,115	465	825	160	50	225	580	375	715	3,345
2012 to 2013	10,345	2,045	350	790	no data	no data	240	460	345	715	3,350
All Other Groups											
2010 to 2011	5,985	5,600	1,200	850	230	45	95	735	110	1,565	2,810
2011 to 2012	6,465	6,805	1,045	855	255	45	165	895	125	2,175	3,120
2012 to 2013	6,780	6,775	1,115	900	no data	no data	240	925	130	1,685	3,405
Total											
2010 to 2011	15,995	7,340	1,770	1,645	390	95	215	1,225	500	2,220	5,870
2011 to 2012	17,815	8,920	1,510	1,680	415	95	390	1,475	500	2,890	6,465
2012 to 2013	17,125	8,820	1,465	1,690	no data	no data	480	1,385	475	2,400	6,755

Data Source: AVA Table 3

Table 9.6 shows the outcomes of completed referrals broken down by outcome type (this data is only broken down by client type for adults aged 18 to 64 years) from financial year 2010 to 2011 to financial year 2012 to 2013, although data on outcome type is incomplete for 2012 to 2013. In total, 18,530 outcomes were reported for adults with learning disabilities aged 18 to 64 years in 2012 to 2013 and 19,785 outcomes for other vulnerable adults aged 18 to 64 years, little change from 2011 to 2012.

Because outcome data is so incomplete for 2012 to 2013 (with apparent increases over time for specific outcomes possibly being a function of the decrease over time in the number of unknown outcomes), we will report here the data for 2011 to 2012.

As Table 9.6 shows, in 2011 to 2012 the most common outcome of AVA referrals for adults with learning disabilities aged 18 to 64 was no further action (28.7%), followed by continued monitoring (20.7%) and the outcome of the referral not being known (8.3%); these three outcomes accounted for over half of completed referrals. Other outcomes reported in over 5% of completed referral cases included management of access to the vulnerable adult (7.1%), counselling/training/treatment (7.1%), police action (6.6%) and disciplinary action (6.2%). Less common outcomes included removal from property or service (4.2%), community care assessment (2.6%), exoneration (2.6%), action by contract compliance (1.7%), referred to PoVA list/ISA (1.4%) and criminal prosecution/formal caution (1.1%). The following outcomes were each reported in less than 1% of completed referrals: action by the CQC, referral to registration body, action under the Mental Health Act, referral to MAPPA and referral to court mandated treatment.

This pattern of outcomes is similar to that reported for 2010 to 2011, except for a reduction in the proportion of cases where the outcome was unknown (from 13% in 2010 to 2011 to 8.3% in 2011 to 2012 to 5.9% in 2012 to 2013).

There were some differences in 2011 to 2012 in the outcomes for other vulnerable groups aged 18 to 64 years compared with those reported for adults with learning disabilities aged 18 to 64 years. For example, no further action (40.2% non-LD vs 28.7% LD) was more common for other vulnerable adults, with continuing action (14.8% non-LD vs 20.7% LD) less common.

Table 9.6: AVA statistics 2010 to 2011: outcome of completed referral (AVA Table 9)

Outcome	Age 18 to 64 years								
	Learning disabilities			All other groups			Total		
	2010 to 2011	2011 to 2012	2012 to 2013	2010 to 2011	2011 to 2012	2012 to 2013	2010 to 2011	2011 to 2012	2012 to 2013
Criminal prosecution/ formal caution	210	205	no data	275	330	no data	485	535	no data
Police action	940	1,240	no data	1,415	1,930	no data	2,355	3,170	no data
Community care assessment	580	495	630	490	525	550	1,070	1,020	1,180
Removal from property or service	625	785	855	550	705	715	1,175	1,490	1,570
Management of access to the vulnerable adult	1,115	1,335	no data	860	1,070	no data	1,975	2,405	no data
Referred to PoVA list / ISA	215	270	320	130	175	175	345	445	495
Referral to registration body	60	65	no data	60	60	no data	120	125	no data
Disciplinary action	970	1,170	no data	530	605	no data	1,500	1,775	no data
Action by CQC	110	140	no data	75	105	no data	185	245	no data
Continued monitoring	3,205	3,885	no data	2,100	2,905	no data	5,305	6,790	no data
Counselling/ training/ treatment	1,010	1,335	no data	555	815	no data	1,565	2,150	no data
Referral to court mandated treatment	10	5	no data	15	10	no data	25	15	no data
Referral to MAPPAs	15	20	no data	20	25	no data	35	45	no data
Action under Mental Health Act	50	40	45	90	110	110	140	150	155
Action by contract compliance	160	320	no data	105	155	no data	265	475	no data
Exoneration	340	490	455	340	410	455	680	900	910
No further action	4,575	5,385	5,250	6,030	7,780	7,875	10,605	13,255	13,125
Not known	2,125	1,565	1,095	2,415	1,780	1,545	4,540	3,445	2,640
TOTAL	16,320	18,755	18,530	16,055	19,495	19,785	32,370	38,435	38,315

10. Deprivation of liberty safeguards assessments

Summary

This section summarizes information collected by the NHS Information Centre from PCTs and local authorities concerning DoLS assessments.

- in 2012 to 2013 1,304 completed applications were made under DoLS concerning adults with learning disabilities. Most of these (79.6%) were made by local authorities
- 669 of the applications (51.3%) were granted, a slightly smaller proportion to those granted concerning other adults (55.5%)
- DoLS applications concerning adults with learning disabilities decreased from 1,513 in 2011 to 2012 to 1,304 in 2012 to 2013
- this is in contrast to DoLS applications for other adults, which rose from 9,880 in 2011 to 2012 to 10,583 in 2012 to 2013

DoLS assessments

As of 2012 to 2013, PCTs and local authorities were required to complete returns concerning Deprivation of Liberty Safeguards (DoLS) assessments, introduced as part of the Mental Capacity Act (2005). The Information Centre states that “DoLS provide a framework for approving the deprivation of liberty for people who lack the capacity to consent to treatment or care in either a hospital or care home that, in their own best interests, can only be provided in circumstances that amount to a deprivation of liberty. The legislation provides for an assessment process that must be undertaken before deprivation of liberty may be authorised.”

Statistics concerning requests for such authorisation and whether they were granted or not are available for 2009 to 2010 through to 2012 to 2013, however, it is worth noting that the recording of disability categories changed slightly after the first quarter of data collection in 2010 to 2011 (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 (see <http://www.hscic.gov.uk/catalogue/PUB11379> for access to reports and datasets).

Table 10.1 below shows the number of applications made under DoLS in 2009 to 2010 through to 2012 to 2013 for adults with learning disabilities aged 18+ years and all other adults, broken down by whether the applications were granted or not granted and by whether the application was made by a local authority or a PCT.

In 2012 to 2013 there were a total of 1,304 completed applications made under DoLS concerning adults with learning disabilities, 11% of the total number of applications. Most of the DoLS applications concerning people with learning disabilities (79.6%) were made by local authorities, a smaller proportion to that reported for other adults (70.2%).

Of the applications concerning people with learning disabilities 669 (51.3%) were granted, a slightly smaller proportion to those granted concerning other adults (55.5%). Concerning people with learning disabilities, in 2012 to 2013 a slightly greater proportion of local authority DoLS applications (52.1%) were granted than PCT DoLS (48.1%).

DoLS applications concerning adults with learning disabilities decreased from 1,513 in 2011 to 2012 to 1,304 in 2012 to 2013 (CAGR 2009 to 2010 to 2012 to 2013 -5.6%). This is in contrast to DoLS applications for other adults, which rose from 9,880 in 2011 to 2012 to 10,583 in 2012 to 2013 (CAGR 2009 to 2010 to 2012 to 2013 +18.4%).

Table 10.1: Number of DoLS completed applications granted (G) and not granted (NG) for adults with learning disabilities and all other groups

	2009 to 2010			2010 to 2011			2011 to 2012			2012 to 2013		
	Total apps	G	NG									
Adults with learning disabilities aged 18+												
LA	1103	419	684	1007	545	462	1151	634	517	1038	541	497
PCT	447	235	212	308	167	141	362	180	182	266	128	138
Total	1550	654	896	1315	712	603	1513	814	699	1304	669	635
All other adults aged 18+												
LA	4290	2020	2270	5701	3272	2429	7057	4063	2994	7426	4293	3133
PCT	1317	623	694	1966	967	999	2823	1466	1357	3157	1584	1573
Total	5607	2643	2964	7667	4239	3428	9880	5529	4351	10583	5877	4706
Total adults aged 18+												
LA	5393	2439	2954	6708	3817	2891	8208	4697	3511	8464	4834	3630
PCT	1764	858	906	2274	1134	1140	3185	1646	1539	3423	1712	1711
Total	7157	3297	3860	8982	4951	4031	11393	6343	5050	11887	6546	5341

Data source: Mental Capacity Act (2005), deprivation of liberty safeguards assessments (England) – first, second and third annual reports on annual data

Total apps=total number of applications; G=number of applications granted; NG=number of applications not granted

11. Benefits

Summary

The DWP reports quarterly data on the following benefits; the data here specifically concerns people with learning disabilities.

In the quarter ending May 2013:

- 424,160 people were receiving Disability Living Allowance. From 2002 to 2013, the number of people who are claiming Disability Living Allowance has increased by 5.7% per year
- the estimated annual cost of Disability Living Allowance payments in 2013 was £1.64 billion. This has increased 8.4% from estimated 2012 costs
- 1,510 people were claiming Attendance Allowance. From 2002 to 2013, the number of people who were eligible for Attendance Allowance decreased by 6% per year. The number of people claiming Attendance Allowance has decreased by 3.7% per year
- the estimated annual cost of Attendance Allowance payments in 2013 was £4.8 million. This has decreased 4.2% from estimated 2012 costs

Benefits

- The DWP provides quarterly information on Attendance Allowance (AA) and Disability Living Allowance (DLA) for adults with learning disabilities in Britain. AA is paid to those over 65 who need someone to look after them. DLA consists of 2 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). In the quarter ending May 2013, 1,510 people with learning disabilities were receiving AA (0.1% of the total number of claimants) and 424,160 adults with learning difficulties were receiving DLA (12.8% of the total number of claimants).
- Table 11.1 presents the numbers of people with learning disabilities eligible for each allowance and the number of people claiming each allowance and receiving each allowance for the March to May quarter from 2002 to 2013. Eligibility statistics include those who have had their payment temporarily suspended, for example if they are in hospital.

Table 11.1: Total number of people with learning disabilities in Britain eligible for and claiming Attendance Allowance and Disability Living Allowance

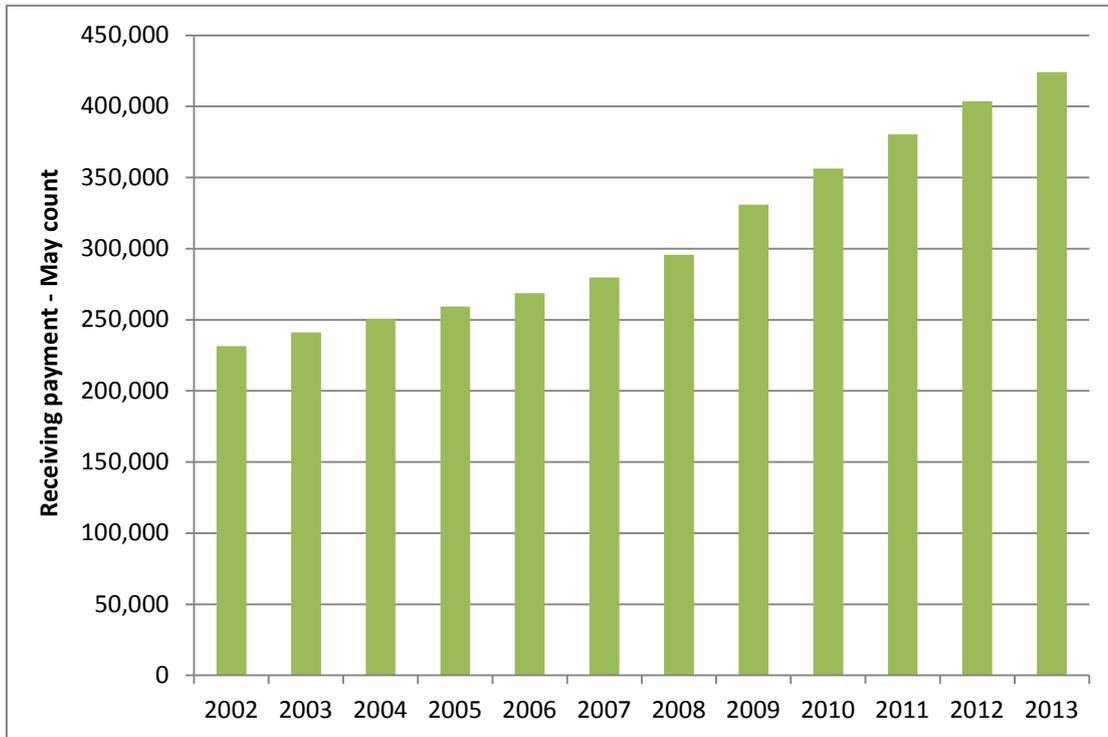
	Attendance Allowance			Disability Living Allowance		
	Eligible	In Payment	% In payment if eligible	Eligible	In payment	% In payment if eligible
May 2002	3,970	2,280	57%	n/a	231,500	
May 2003	3,700	2,160	58%	n/a	241,100	
May 2004	3,560	2,220	62%	n/a	250,700	
May 2005	3,340	2,150	64%	n/a	259,300	
May 2006	3,190	2,080	65%	n/a	268,800	
May 2007	2,950	1,950	66%	n/a	279,800	
May 2008	2,730	1,840	67%	n/a	295,700	
May 2009	2,580	1,790	69%	n/a	331,000	
May 2010	2,490	1,760	71%	n/a	356,400	
May 2011	2,360	1,700	72%	383,400	380,250	99%
May 2012	2,170	1,590	73%	407,000	403,720	99%
May 2013	2,010	1,510	75%	427,520	424,160	99%
Compound Annual Growth Rate	-6.0%	-3.7%		+5.6%	+5.7%	

Note: All Attendance Allowance and, from May 2011, Disability Living Allowance figures are based on a complete census of claimants. Previous Disability Living Allowance figures are based on a 5% sample of claimants.
Source: DWP Tabulation Tool <http://83.244.183.180/100pc/tabtool.html>

- As Table 11.1 shows, the number of people with learning disabilities who are claiming DLA has increased by 5.7% per year from 2002 to 2013, with almost everyone eligible for DLA actually claiming (99%) (see also Figure 11.1).
- DLA consists of 2 components which are assessed and paid separately. In the publicly available national statistics, figures for people with learning disabilities 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 DLA in the quarter ending May 2013, 114,610 people with learning disabilities were claiming at the higher rate (average claim of £109.45 per week; £5,691.40 per year), 207,710 people were claiming at the middle rate (£73.43 per week; £3,818.36), 66,120 people were claiming at the lower rate (£38.49 per week; £2,001.48 per year) and 35,720 people were claiming at the 'nil' rate (£29.59 per week; £1,538.68 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 disabilities for 2013 was approximately £1.64 billion, an 8.4% increase from estimated 2012 costs.

Figure 11.1: number of people with learning disabilities receiving DLA payment (May) 2002 to 2013



- In contrast, from 2002 to 2013 the number of people with learning disabilities who are eligible for AA has declined by 6% per year, and the number of those claiming has declined by 3.7% per year. The percentage of those eligible for AA who are claiming has risen from 57% in 2002 to 75% in 2013.
- In the quarter ending May 2013, 480 people with learning disabilities over 65 were claiming AA at the higher rate (average claim of £78.86 per week; £4,100.72 per year) and 1,020 people were claiming at the lower rate (£52.94 per week; £2,752.88 per year). Using these figures indicates that the estimated annual cost of AA payments to people with learning disabilities for 2013 was approximately £4.8 million, a 4.2% reduction from estimated 2012 costs.

12. Family carers

Summary

A variety of sources provide information relating to family carers of people with learning disabilities.

Health and Social Information Centre statistics, based on returns from local authorities, report that:

- in 2012 to 2013 a total of 40,845 carers were offered an assessment or review and of these, 37,930 (93%) took place.
 - of those that took place:
 - 22,285 (59%) involved a joint assessment or review with the person with learning disabilities
 - 5% were for an adult with learning disabilities who was 65 years old or older
 - after an assessment took place, 35,930 (95%) carers received services or information:
 - 20,465 (54%) of carers received services (eg short breaks)
 - 15,465 (41%) only received information and advice. This has increased from 23% in 2007 to 2008, an average increase of 3.5% per year

The Personal Social Services Survey of Adult Carers in England (2012 to 2013) found that:

- 48% of carers of an adult with learning disabilities spend 100 or more hours a week caring for that person
- 73% of carers of an adult with learning disabilities had been caring for more than 20 years
- 29% were not in paid employment because of their caring responsibilities
- for 88% of carers the person they care for usually lives with them
- rates of reported carer dissatisfaction are low. Of carers of people with learning disabilities, 11% said that they are fairly, very or extremely dissatisfied. This compares with 9% for all carers in England

Referrals, assessments and packages of care (RAP) data

The NHS Information Centre publishes Community Care Statistics - referrals, assessments and packages of care (RAP) data about the numbers of assessments or reviews completed for carers (RAP form C1) as well as the information and services provided as a result of these assessments (RAP form C2). From 2007 to 2008 this data can also be broken down by the age group of the person with learning disabilities being cared for, although not by carers' age group.

Table 12.1: estimated numbers of carers of an adult with learning disabilities for whom assessments or reviews were completed

	Carers assessed or reviewed separately			Carers assessed or reviewed jointly with client			Carers declining an assessment		
	All client ages	Age 18 to 64	Age 65 and over	All client ages	Age 18 to 64	Age 65 and over	All client ages	Age 18 to 64	Age 65 and over
2006 to 2007	14,000			20,000			2,400		
2007 to 2008	15,000	14,000	1,400	21,000	19,000	2,000	2,500	2,200	300
2008 to 2009	17,000	16,000	1,100	23,000	21,000	1,500	2,300	1,900	500
2009 to 2010	16,150	15,090	1,060	21,740	20,505	1,235	3,280	3,015	265
2010 to 2011	18,255	17,170	1,080	20,890	19,495	1,395	3,485	3,335	150
2011 to 2012	17,505	16,130	1,375	21,485	20,145	1,340	2,855	2,235	615
2012 to 2013	15,645	14,705	940	22,285	21,195	1,090	2,915	2,755	155
Compound Annual Growth Rate 2007 to 2008 to 2012 to 2013	+0.9%	+1.0%	-7.7%	+1.2%	+2.2%	-11.4%	+3.1%	+4.6%	-12.4%

Source: RAP Table C1.2

Table 12.1 shows that in 2012 to 2013 an estimated 40,845 carers were offered an assessment or review, of which 37,930 (93%) were completed. Overall slight increases from financial year 2007 to 2008 to financial year 2012 to 2013 for carers of adults aged 18 to 64 do not reveal the details of trends within this timeframe. The number of assessments or reviews offered and completed rose by an average of 8% per annum between 2006 to 2007 and 2008 to 2009 after which both have shown a marginal decline (2008 to 2009 to 2012 to 2013 CAGR for number of completed assessments -1.3%, offered assessments -0.9%). The completion rate has fluctuated between 92-95% during this period.

Of the assessments completed:

- 22,285 (59%) involved a joint review/assessment with the client with learning disabilities, increasing from 55% in 2011 to 2012
- 2,030 (5%) took place where the adult with learning disabilities was aged 65 or over. The percentage of assessments/reviews involving older adults with learning disabilities has fluctuated between 3% and 7% since 2008 to 2009

Table 12.2: Estimated numbers of carers of an adult with learning disabilities receiving services and information

	Total number of carers receiving services or information			Services, including breaks for the carer and/or other carers' specific services			Information and advice only		
	All client ages	Age 18 to 64	Age 65 and over	All client ages	Age 18 to 64	Age 65 and over	All client ages	Age 18 to 64	Age 65 and over
2006 to 2007	30,000			20,000			9,700		
2007 to 2008	34,000	31,000	2,800	25,000	23,000	1,900	8,300	7,500	800
2008 to 2009	35,000	33,000	2,200	25,000	24,000	1,400	10,000	9,300	800
2009 to 2010	36,340	34,175	2,165	23,040	21,770	1,270	13,300	12,405	895
2010 to 2011	37,015	34,655	2,355	21,650	20,400	1,250	15,360	14,255	1,105
2011 to 2012	35,875	33,520	2,355	20,665	19,425	1,240	15,210	14,095	1,115
2012 to 2013	35,930	34,010	1,925	20,465	19,490	980	15,465	14,520	945
Compound Annual Growth Rate 2007 to 2008 to 2012 to 2013	+1.1%	+1.9%	-7.2%	-3.9%	-3.3%	-12.4%	+13.3%	+14.1%	+3.4%

Source: RAP Table C2.2

Table 12.2 shows that in 2012 to 2013, 35,930 carers received some form of services or information, 95% of those carers who received an assessment or review. The percentage of carers receiving services or information following assessment has fluctuated between 88% and 96% since 2006 to 2007. Of the 35,930 carers receiving services or information in 2012 to 2013:

- 20,465 received services (eg short breaks), 54% of carers with a completed assessment. The percentage of carers receiving services following assessment rose from 59% to 69% between financial year 2006 to 2007 and financial year 2007 to 2008. From financial year 2007 to 2008 to financial year 2011 to 2012 this declined by an average of 4 percentage points a year to 53%, with a small increase of 1% seen from financial year 2011 to 2012 to financial year 2012 to 2013. The total number of carers receiving services increased from financial year 2006 to 2007 (20,000) to financial year 2008 to 2009 (25,000), but has since decreased to 20,465 in 2012 to 2013 (CAGR 2008 to 2009 to 2012 to 2013 -4.9%)
- 15,465 carers received information and advice only, 41% of carers with a completed assessment. The percentage of carers only receiving information or advice following assessment declined from 29% to 23% between 2006 to 2007 and 2007 to 2008. Since then it has increased by an average of 3.5 percentage points a year. The total number of carers only receiving information has increased relatively steadily from 2006 to 2007 (CAGR 2007 to 2008 to 2012 to 2013 +13.3%)

Adult social care outcomes framework (ASCOF)

The set of national indicators (NI) for English local authorities and local authority partnerships which ran from financial year 2008 to 2009 to financial year 2010 to 2011 included NI 135. NI

135 calculated the number of carers (caring for someone aged 18 to 64) receiving needs assessment or review and a specific carers' service, or advice and information, within a given year, as a percentage of people (aged 18 to 64) receiving a community-based service. This data has been reported previously in 'People With Learning Disabilities in England 2012'. The National Indicator Set ceased on 31 March 2011 and has now been replaced by the Adult Social Care Outcomes Framework¹², (ASCOF). The ASCOF includes 4 indicators relating to carers which have been taken from the Personal Social Services Survey of Adult Carers in England (2012 to 2013) as indicated in the section below.

Personal social services survey of adult carers in England: 2012 to 2013

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 to 2013. The survey is published by the Health and Social Care Information Centre and includes carers aged 18 or over who are caring for someone aged 18 or over who is in receipt of services funded (in whole or in part) by Social Services¹³. The experiences of the carers of children or child carers are not included in this dataset.

The 2009 to 2010 Survey¹⁴ reported in 'People with Learning Disabilities in England 2012' was a pilot study which 90 CASSRs took part in voluntarily and following the pilot study the number of questions was reduced from 58 to 27. The survey is now listed on the Department for Communities and Local Government single data list as one of the data returns local authorities are required to submit under current arrangements. The survey seeks carers' thoughts and opinions on a number of topics that are considered to be indicative of a balanced life alongside their caring role.

The survey features heavily in the ASCOF, being used to populate four of the outcome measures:

- 1D: carer reported quality of life
- 3B: overall satisfaction of carers with social services
- 3C: the proportion of carers who report they have been included or consulted in discussions about the person they care for
- 3D: the proportion of people who use services and carers who find it easy to find information about services

These ASCOF outcome measures are included in this section.

In total 57,860 people out of a sample of 126,755 carers of social care users responded to the survey (response rate 46%). Of 57,100 carers who responded to the question 'Does the person you care for have...(eg dementia, physical disability)', for 6,220¹⁵ (10.9%) the primary

¹² The Adult Social Care Outcomes Framework - Handbook of definitions

<https://www.gov.uk/government/publications/the-adult-social-care-outcomes-framework-handbook-of-definitions>

¹³ Data tables (Table U2: Answers by Demographics) available at <http://www.hscic.gov.uk/pubs/psscscarerssurvey1213f>

¹⁴ Personal Social Services of Adult Carers – England 2009-10, available at <http://www.hscic.gov.uk/pubs/psscscarerssurvey0910>

¹⁵ The number of carers for whom the primary client group is learning disabilities is not available, this question has the highest number of carers of a person with learning disabilities (primary client group) responding

client group of the cared for person was learning disabilities. Across all primary client groups, 16.5% of carers reported that the person they care for has learning disabilities or difficulties.

Carers of people with learning disabilities or difficulties- general characteristics

- 10.9% of carers in England care for someone for whom their primary client group is learning disabilities or difficulties
- 2.1% of all carers state that they have learning disabilities or difficulties
- 6% of the carers of people with learning disabilities or difficulties state that they also have learning disabilities/ difficulties

For carers where the primary client group of the person they care for is learning disabilities or difficulties:

- 48% spend 100 or more hours a week caring for that person, compared with 34.8% for all carers in England
- 72.8% of carers of a client with learning disabilities had been caring for more than 20 years, compared with an average of 18.5% for all carers in England
- 29.3% were not in paid employment because of their caring responsibilities, compared with 19.2% for all carers in England
- for 88.2% of carers the person they care for usually lives with them rather than somewhere else, compared with an average of 71.2% for all carers in England

Access to support or services

In the previous 12 months, for carers where the primary client group of the person they care for is learning disabilities or learning difficulties:

- 11.3% found it very easy to find information and advice about support, services and benefits, 33% found it fairly easy, 17.8% found it fairly difficult and 8.3% found it very difficult to find this information and advice (29.6% had not tried to find information or advice)
- 19.8% of carers found the information and advice they had received to be very helpful, 40.9% found it quite helpful, 6.5% found it quite unhelpful and 3% found it very unhelpful (29.8% had not received information or advice)
- 31.4% felt they had always felt involved or consulted in discussions about the support or services provided to the person they care for, 25.5% said they usually felt involved or consulted, 18.6% said they sometimes felt involved or consulted and 5.7% said they never felt involved or consulted (18.8% had no discussions)
- in terms of support or services to help carers 48.3% of carers said they had used information and advice, 29.2% had used support from carers groups or someone to talk to in confidence, and 4.6% had used training for carers

- 40.5% had used a support or service to take a break from caring that lasted longer than 24 hours and 30.6% to take a rest from between 1 hour and 24 hours
- 41.9% of carers felt they had encouragement and support, 41.4% felt they had some encouragement and support but not enough and 16.7% felt they had no encouragement and support

Table 12.3: overall satisfaction for the support or services carers and the person they care for have received from Social Services in the last 12 months (%), England, 2012 to 2013							
	Satisfied				Dissatisfied		
	Extremely	Very	Fairly	Neither	Fairly	Very	Extremely
Carers of person with learning disabilities/difficulties (13% had not received support or services)	11.4	21.1	30.3	13.2	5.7	2.5	2.8
England carers average (15.5% had not received support or services)	13.2	22.9	28.5	11.3	4.6	1.9	2.0

Table 12.3 shows that carers of people with learning disabilities or difficulties are slightly less likely to be extremely satisfied (11.4% compared with 13.2% for all carers in England) or very satisfied (21.1% compared with 22.9% for all carers) with the support or services they and the person they care for have received. While rates of dissatisfaction are low, carers of people with learning disabilities or difficulties have slightly higher levels of dissatisfaction with support or services received from social services compared with the average for all carers in England. Overall, 11% state that they are fairly, very or extremely dissatisfied compared with 8.5% for all carers in England.

Carer-reported quality of life

In the ASCOF, a summary of carer-reported quality of life is given. This measure combines individual responses to 6 questions in the Carers' Survey measuring different outcomes related to overall quality of life. A higher score indicates a better self-rated quality of life. In 2012 to 2013, the mean score for carers of an adult with learning disabilities was 8.1 (on a 1-10 scale), the same as the overall mean for England.

Glossary

AA	Attendance Allowance
ASC -CAR	adult social care – combined activity returns
ASCOF	Adult Social Care Outcomes Framework
AVA	abuse of vulnerable adults
CAGR	compound annual growth rate
CASSRs	councils with adult social services responsibilities
CIPOLD	Confidential Inquiry into premature deaths of people with learning disabilities
CQC	Care Quality Commission
DfE	Department for Education
DLA	Disability Living Allowance
DoLS	Deprivation of liberty safeguards
DWP	Department of Works and Pensions
FCEs	finished consultant episodes
LD	learning difficulties
MAPPA	multi-agency public protection arrangements
MLD	moderate learning difficulty
NASCIS	National Adult Social Care Intelligence Service
NI	national indicator
PCT	Primary Care Trust
PMLD	profound multiple learning difficulties
PoVA	protection of vulnerable adults
PSSEX	personal social services expenditure data
QOF	quality and outcomes framework
RAP	referrals, assessments and packages of care
SEN	special educational needs
SENCO	special educational needs coordinator
SLD	severe learning difficulties
SMRs	standardized mortality ratios
VPN	Valuing People Now

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Section 2 - number of people with learning disabilities

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