



Centre for Disability Research

# People with Learning Disabilities in England

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# Summary

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The aim of this report, which has been commissioned by Mencap, is to summarise information that is available from *nationally representative* data sources on the life experiences and services used by people with learning disabilities in England. These data sources include information on service activity collected by the Department of Health and other government departments, and information that can be extracted from large scale nationally representative surveys

## How Many People with Learning Disabilities Are There in England?

It is not possible to estimate the number of number of adults with learning disabilities in England either from information held by centrally government departments or from large-scale population based surveys.

For children, however, information collected by the DCFS suggests that (as of January 2006), 210,510 (2.6%) pupils were identified as having a primary special educational need (SEN) associated with learning disabilities. This will, however, be a significant under-estimate of the actual prevalence due to the failure to report data collected on children at the School Action stage in the assessment of SEN and failure to report data collected on secondary SEN.

Given this lack of information, we were commissioned by the Department of Health in 2004 to derive robust estimates of current and future numbers of people with learning disabilities in England. We estimated that 985,000 people in England have a learning disability (2% of the general population). This figure includes 828,000 adults (aged 18 or more). Of these adults, we estimated that 177,000 were known users of learning disability services in England (equivalent to 0.47% of the adult population)

In *Valuing People*, the Department of Health estimated that 65,000 children and 145,000 English adults have severe or profound learning disabilities, and 1.2 million have mild or moderate learning disabilities. The Department of Health estimate for children (for which no age range is given) with severe or profound learning disabilities is 67% higher than DCFS data on the SEN of pupils.

Given that the large majority of service users have severe or profound learning disabilities, the Department of Health estimate for adults with severe or profound learning disabilities (145,000) is consistent with our estimate of 177,000 known users of learning disability services (most, but not all, of whom will have severe or profound learning disabilities). The Department of Health estimate for adults with mild/moderate learning disabilities is significantly higher than our estimate. This discrepancy is most probably due to the use by the Department of Health of the same prevalence estimate across all age groups. In our estimates we progressively adjusted prevalence estimates to take into account the increased mortality of people with learning disabilities, particularly in older age groups.

### *Are the Numbers of People with Learning Disabilities Changing?*

Given that no accurate records are kept of the number of people with learning disabilities in England, it is not possible to determine whether these numbers are changing. Factors that could lead to a change in the number of people with learning disabilities in England include changes in the future size and composition of the English population, and potential changes in the incidence and prevalence of learning disabilities.

It is predicted that that English population will rise from 50.9 million in 2007 to 53.5 million in 2017 (+5%) and 56.0 million in 2027 (+10% from 2007). If we assume that there will be no changes in the incidence and prevalence of learning disabilities, these changes in the general population will result in equivalent changes in the population of people with learning disabilities.

In our work for the Department of Health, we argued that three factors are likely to lead to an increase in the age-specific prevalence rates for adults with learning disabilities in England over the next two decades. These are to: (1) the increase in proportion of younger English adults who belong to South Asian minority ethnic communities; (2) increased survival rates among young people with severe and complex disabilities; (3) reduced mortality among older adults with learning disabilities. By combining the effects of these changes with the effects of general demographic change we estimated modest but sustained growth over the next two decades in both the numbers of people with learning disabilities known to learning disability services (11% over the decade 2001-2011, 14% over the two decades 2001-2021).<sup>a</sup> These projections were used by the Department of Health to justify the need to review the organisation of social care in England and are broadly consistent with the predictions made in *Valuing People*.

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<sup>a</sup> The predicted slowing down in the growth of the population of people with learning difficulties reflects the impact of decreased child population in the period up to 2017 and the ageing of the general population

## The Life Experiences of Adults with Learning Disabilities

In *Valuing People*, the Department of Health made a commitment to 'commission a national survey of people with learning disabilities ... in order to improve our knowledge and provide a stronger baseline against which to evaluate the impact of *Valuing People*'. The results of this survey, which was undertaken in 2003/4, provide the most robust information available on the 'typical' life experiences of people with learning disabilities in England. In the following sections we present new analyses of these data that summarise key survey results separately for people with mild/moderate learning disabilities, people with severe learning disabilities and people with profound and multiple learning disabilities.

### *Accommodation*

The majority of people with severe and profound multiple learning disabilities were living with a parent. The majority of people with mild/moderate learning disabilities were living with a parent or other relative. People with more severe learning disabilities were more likely to be living in Residential Care Homes and NHS accommodation. The majority of people in supported accommodation had no choice over either who they lived with or where they lived. This was particularly the case for people with more severe learning disabilities. While the majority of people did have acceptable levels of privacy, a substantial minority did not. Again, this was particularly the case for people with more severe learning disabilities.

### *Employment*

Over four in five (83%) of people with learning disabilities of working age were unemployed. The chances of having any paid employment were, however, much greater for people with less severe learning disabilities. 28% of mild/moderate learning disabilities had some form of paid employment compared to 10% of people severe with learning disabilities and 0% of people with profound and multiple learning disabilities.

### *Education & Training*

Just over one in three people (36%) were undertaking some form of education or training. This was markedly higher among people with mild/moderate learning disabilities (36%) and people with severe learning disabilities (38%) than among people with profound and multiple learning disabilities (14%). Just over one in three people (39%) attended a day centre. This was markedly higher among people with profound and multiple learning disabilities (66%) and people with severe learning disabilities (49%) than among people with mild/moderate learning disabilities (24%).

## *Hardship & Deprivation*

People with learning disabilities living in private households are much more likely to live in areas characterised by high levels of social deprivation. People living in private households were also much more likely to experience material and social hardship than people in supported accommodation services. Also, people with mild/moderate learning disabilities were much more likely to experience material and social hardship than people with severe or profound and multiple learning disabilities.

## *Families, Friends & Relationships*

People with learning disabilities were less likely than people without learning disabilities to have contact with friends and members of their family that they were not living with. The latter is most likely to be due to people with learning disabilities being much more likely to be still living with their families than people without learning disabilities.

## *Being Part of the Community*

People with profound and multiple learning disabilities were notably less likely to participate in a range of leisure and community-based activities than people with mild/moderate or severe learning disabilities.

Less than one in three people with learning disabilities (31%) reported that they voted in the 2001 general election. Voting was higher among people with mild/moderate learning disabilities (42%) than among people with severe learning disabilities (27%) and people with profound and multiple learning disabilities (4%).

Just over one in four people with learning disabilities (28%) reported having attended a self-advocacy meeting. This was higher among people with mild/moderate learning disabilities and people with severe learning disabilities (both 29%) than among people with profound and multiple learning disabilities (15%).

Participants were asked whether in the last year anybody had been rude or offensive to them because they have a learning disability. Nearly one in three people (32%) said someone had been rude to them. This was higher among people with mild/moderate learning disabilities (33%) and people with severe learning disabilities (31%) than among people with profound and multiple learning disabilities (24%).

Overall, nearly one in ten people (9%) said they had been the victim of crime in the last year. This was higher among people with mild/moderate learning disabilities (12%) and people with severe learning disabilities (8%) than among people with profound and multiple learning disabilities (4%). This is much less than the chances of being a victim of crime as reported in the general population in the 2003/4 in the British Crime Survey (26%).

## *Health & Well-Being*

Just under one in five (19%) people with learning disabilities reported that they smoked cigarettes. This was higher among people with mild/moderate learning disabilities (30%) than people with severe learning disabilities (11%) and people with profound and multiple learning disabilities (4%). Rates of smoking were also higher among people living in private households.

One in five (20%) reported that they exercised three or more times a week. Again, this was higher among people with mild/moderate learning disabilities (23%) than people with severe learning disabilities (18%) and people with profound and multiple learning disabilities (9%). Rates of exercising were also higher among people living in private households.

Rates of use of all health services were higher for people living in supported accommodation services than for people living in private households.

## **National Datasets**

Several sources of national statistical information relevant to people with learning disabilities are collected for Government departments. These data largely concern aspects of service activity rather than people's life experiences. Some of the more relevant national statistics are reported here using the latest available statistics (typically for 2005-2006), with comparisons to 2000-2001 where possible.

### *Accommodation*

In 2005-2006 there were 3,927 available NHS overnight beds in England for people with learning disabilities (down 38% from 2000-2001), of which 3,291 were occupied. In total, these beds constitute 2.2% of the total number of overnight beds available in the NHS. Specific types of bed available included: 208 short-stay beds for children; 26 long-stay beds for children; 1,188 short-stay beds for other ages; 1,978 long-stay beds for other ages; 526 secure beds for other ages.

In 2006, the Mental Health Act Commission conducted Count Me In, a comprehensive census of all mental health and learning disabilities inpatients in NHS and independent sector hospital providers in England and Wales. Within English services self-identified as providers for people with learning disabilities, 4,435 people were identified, 3,505 in NHS services and 930 in independent sector services. Most people in learning disability provider services had an informal legal status (64%), were deemed incapable of giving consent (58%), and had been resident in their service for a considerable length of time (35% for more than 5 years).

At 31 March 2006, there were 35,260 council supported residents with learning disabilities aged 18-64 (60% of all council supported resident adults in this age group), a 13.5% increase from 2001. These included:



3,200 people in council staffed residences (down 45% from 2001); 28,080 people in independent sector registered residential homes (up 23% from 2001); 1,840 people in independent sector nursing homes (up 87% from 2001); 2,140 people in unstaffed or other types of home (up 56% from 2001).

Personal Social Services Expenditure and Unit Costs for 2005-2006 reports the following unit costs for residential services for adults with learning disabilities in England: Nursing care unit cost £843 per person per week (up 12.4% from 2000-2001); Residential care unit cost £895 per person per week (up 26.8% from 2000-2001).

Gross personal social services expenditure on residential services for adults with learning disabilities aged under 65 includes: £77.1 million on nursing home places (up 120% from 2000-2001); £1,393.6 million on residential care home places (up 59% from 2000-2001); £191.2 million on supported/other residential places (up 86% from 2000-2001).

### *Community Services*

Community Care Statistics: Referral, Assessment and Packages of Care for 2005 -2006 reports several statistics concerning community services for people with learning disabilities, largely provided by councils with social service responsibilities.

In 2005-2006, 8,000 adults with learning disabilities aged 18+ were reported as new clients receiving an assessment (1.2% of the total number of new adults receiving a social services assessment in 2005-2006). In total, social services departments spent £205.4 million on assessment and care management for adults with learning disabilities aged under 65 in 2005-2006 (up 96% from 2000-2001).

134,000 adults with learning disabilities aged 18+ received some form of service from the local authority in 2005-2006 (up 23% from 2000-2001), including 103,000 receiving community-based services (up 13% from 2000-2001). More specifically: 27,000 people received home care (up 197% from 2000-2001); 58,000 people received day care (unchanged from 2000-2001); 1,100 people received meals (down 48% from 2000-2001); 12,000 people received overnight respite not in the client's home (up 9% from 2000-2001); 5,800 people received short-term residential services (not respite) (up 18% from 2000-2001); 5,500 people received direct payments (up 2,650% from 2000-2001); 38,000 people received professional support (up 52% from 2000-2001)<sup>b</sup>; 6,000 people received equipment and/or adaptations (up 67% from 2000-2001); 17,000 people received an 'other' type of service (up 49% from 2000-2001).

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<sup>b</sup> This includes any professional activity undertaken by the care manager, social worker or other professional staff, such as Occupational Therapists, that is beyond the process of care management.

Gross personal social services expenditure on community-based services for adults with learning disabilities aged under 65 includes: £288.1 million on home care (up 160% from 2000-2001); £620.5 million on day care (up 37% from 2000-2001); £1.3 million on meals (up 30% from 2000-2001); £42.2 million on direct payments (up 2,538% from 2000-2001); £0.8 million on equipment and/or adaptations (up 13% from 2000-2001); £93.5 million on other services (up 41% from 2000-2001).

In total, including all components of social services expenditure for adults with learning disabilities aged under 65, the gross total personal social expenditure in 2005-2006 was £2,914.6 million (15.6% of all personal social services expenditure). Including Supporting People expenditure, the total rises to £3,110.3 million, 23.4% of all personal social services expenditure including Supporting People.

In 2005-2006, 31,000 assessments/reviews involving carers of adults with learning disabilities were completed (9.1% of the total number of completed carer assessments/reviews), with 3,000 carers declining an assessment or review.

### *Health Services*

From January to March 2007, 438 referrals were made by GPs and 965 referrals from other sources for an outpatient hospital appointment with a learning disability specialist. In 2005-2006, there were 55,574 attended outpatient appointments with clinical specialists with a primary expertise in learning disabilities (down 32% from 2000-2001). There were 10,945 admissions to inpatient NHS services by people with learning disabilities in 2005-2006 including 1,456 emergency admissions.

### *Advocacy*

In 2005-2006, councils spent an average £95.00 on advocacy for people with learning disabilities per person with learning disabilities known to the council (up 58% from 2000-2001).

### *Employment*

In 2005-2006, 0.4 adults with learning disabilities of working age were in paid employment per 1,000 of the local working age population. This is equivalent to approximately 12,500 adults with a learning disability of working age (or 8% of the estimated total population of adults with a learning disability of working age). A similar number (0.4 per 1,000) were in voluntary employment.

### *Benefits*

In the quarter ending November 2006: 3,100 people were claiming Attendance Allowance (0.2% of the total number of claimants); 263,050 adults with learning difficulties were receiving Disabled Living Allowance (9.2% of the total number of claimants).

## Variation

As highlighted in Rob Greig's overview report of the first four years of *Valuing People*<sup>26</sup>, almost all national statistics show large geographical variations. To account for differences in locality population numbers and eligibility criteria, the Commission for Social Care Inspection Data Analysis Tool (Table 9 ref 38)<sup>20</sup> contains several indicators that are expressed as a proportion of the total local population of the appropriate age – these give a useful perspective on cross-council variation. Although such variations can be found on almost any indicator, some examples include:

- The top quartile of councils spend twice as much per head of local population on advocacy for adults with learning disabilities than the bottom quartile of councils.
- The number of adults with learning disabilities in paid work – in the top quartile of councils the paid employment rate was 2.5 times that of the bottom quartile of councils.
- Adults with learning disabilities were more than twice as likely to have regular short-term breaks written into their care plan in the top quartile of councils compared to the bottom quartile of councils.

## Measuring Outcomes

The Department of Health recently commissioned a research project with the overall objective of helping the Government to develop ways of evaluating the impact of *Valuing People* at a national level<sup>1, 23, 24, 25</sup>, focusing on the adequacy of currently available national statistics, the views of different stakeholders on what information should be collected, and developing practical methods to collect more relevant national information to evaluate the impact of *Valuing People*. Five major conclusions were drawn from the project as a whole:

1. People with learning disabilities, family carers and existing policies all emphasise the importance of outcomes (whether people's life experiences reach generally accepted standards of acceptability and decency, and whether people are in control of their lives and achieving their aspirations).
2. Existing information collected nationally concerning people with learning disabilities does not reflect the importance of outcomes, being largely focused on the resources and activities of particular services.
3. A major shift will be required in both the type of information collected and the methods used to collect it if outcomes are to be placed at the heart of national data collection.
4. The methods and technology required to collect outcome information from people with learning disabilities and their families already exist; the major challenge is to translate existing knowledge into feasible methods for collecting national information.

5. People with learning disabilities and family carers need to have a much bigger role in both deciding the priorities for information collection and accessing this information.

On the basis of these conclusions, the project report proposes five principles for the development of national performance indicators concerning people with learning disabilities:

- 1) National statistics and performance indicators should place a much greater emphasis on outcomes (the life experiences of people with learning disabilities) rather than on resources or service activities.
- 2) People with learning disabilities and family carers should be given a central role in shaping the outcomes agenda, particularly in terms of which types of information should be collected, and should be able to access and use the information obtained.
- 3) Data collection systems should be designed around the totality of the lived experience of people with learning disabilities rather than producing aggregate statistics concerning the activities of specific services.
- 4) National statistics should reflect current Government policies and their associated objectives.
- 5) National statistics should be able to document potential areas of inequality; between people with learning disabilities and the general population; and within the population of people with learning disabilities.

The national survey of adults with learning difficulties<sup>10</sup> does largely work to these principles, and thus provides meaningful information on the life experiences of adults in England. However, the sampling strategies, questioning methods and question content used in this national survey were unique and are unlikely to be repeated routinely. National statistics collected on a regular basis for Government do not work to the five principles outlined above, making 'state of the nation' statistics concerning the lived experience of people with learning disabilities of limited utility in judging the success (or otherwise) of Government policy.

As the national survey of the life experiences of adults with learning difficulties and other international large-scale data collection projects illustrate, it is perfectly possible to develop and use quantitative outcome indicators that are reliable, valid and feasible to collect – the challenge is to find ways for such indicators to retain their reliability and validity when collected on a routine basis, and to harness the political will to do so.

# Background

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The aim of this report, commissioned by Mencap, is to summarise information that is available from *nationally representative* data sources on the life experiences and services used by people with learning disabilities in England. These data sources include information on service activity collected by the Department of Health and other government departments, and information that can be extracted from large scale nationally representative surveys<sup>1</sup>.

# How Many People with Learning Disabilities Are There in England?

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It is not possible to estimate the number of number of people with learning disabilities in England either from information held by centrally government departments or from large-scale population based surveys.

National statistical returns collected by government departments relate to specific services used by people with learning disabilities. For adults, for example, information is collected annually in the Referrals, Assessments and Packages of Care (RAP) from Councils with Social Service Responsibilities on people with learning disabilities using social care services. However, none of these data collections are comprehensive and none of these sets of data are linked. As such, it is not possible to estimate the number of number of adults with learning disabilities in England.

For children, however, information is collected on the special educational needs (SEN) of all children in maintained schools and non-maintained special schools. The latest information (from January 2006) indicates that, of these 8.2 million pupils, 171,740 (2.1%) had an identified primary SEN associated with moderate learning difficulty, 30,440 (0.4%) had an identified primary SEN associated with severe learning difficulty and 8,330 (0.1%) had an identified primary SEN associated with profound and multiple learning difficulty.<sup>2</sup> In total, 210,510 (2.6%) pupils were identified as having a primary SEN associated with learning disabilities.

This will, however, be a significant under-estimate of the actual prevalence for two reasons. First, data is only reported for children with either a Statement of SEN or at School Action Plus in the assessment of SEN. While data is collected on the nature of SEN for children at the School Action stage in the assessment of SEN, this data is not reported. This will have most impact on estimating the numbers of children with less severe learning disabilities. Second, data is only reported on the child's *primary* SEN. Although data is collected on secondary SEN, this data is not reported.<sup>c</sup>

Given that it is not possible to estimate the number of number of people with learning disabilities in England either from information held by centrally government departments or from large-scale population based surveys, we were commissioned by the Department of Health in 2004 to derive robust estimates of current and future numbers of people with learning disabilities in England.<sup>3 4</sup>

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<sup>c</sup> In order to illustrate the potential significance of this omission we have analysed PLASC data from one Local Authority. In this locality, 6.4% of children with a primary SEN not directly associated with learning disabilities (e.g., behavioural, emotional & social difficulties, autistic spectrum disorder, sensory impairment, physical difficulties) were reported to have a secondary SEN associated with learning disabilities. Extrapolating this to national data would increase the estimated overall prevalence of learning disabilities to 236,000 (2.9%) pupils.

To do this we first extracted information from locally held learning disability 'registers' on the age and gender of 15,000 people with learning disabilities who are known to services in 24 Councils with Social Service Responsibilities covering a population base of 3.2 million people (7% of the population of England). We then combined this with population data from the 2001 Census. We estimated that 177,000 adults (aged 18 or over, 0.47% of the total adult population) were known users of learning disability services in England. Of these, 26,000 were aged 60 or more.<sup>d</sup>

However, we know that many adults with (primarily mild) learning disabilities do not use specialist learning disability services.<sup>5 6</sup> This may reflect a lack of 'need', a wish to avoid the stigmatisation associated with such services or that people are deemed 'ineligible' for social care services. As a result, we attempted to estimate the true numbers of people with learning disabilities in England. We estimated that 985,000 people in England have a learning disability (2% of the general population). This included 828,000 people aged 18 or more, of whom 174,000 were people aged 60 or more. It also included the 177,000 people aged 18 or more who were using services for people with learning difficulties.

In *Valuing People*,<sup>7</sup> the Department of Health estimated that 65,000 children and 145,000 English adults have a severe or profound learning disabilities, and 1.2 million English adults have mild or moderate learning disabilities. While the basis for these estimates is not stated, it appears likely that they were derived by applying a standard prevalence rate unadjusted for age (2.5% for mild or moderate learning disabilities) to population predictions for 1999.

The Department of Health estimate for children (for which no age range is given) with severe or profound learning disabilities is 67% higher than DCFS data on the SEN of pupils. It is difficult to reconcile this apparent discrepancy as the DCFS figure is an underestimate (for the reasons pointed out above) and the Department of Health estimate for 'children and young people' includes pre-school children.

Given that the large majority of service users have severe or profound learning disabilities, the Department of Health estimate for adults with severe or profound learning disabilities (145,000) is consistent with our estimate of 177,000 known users of learning disability services. The discrepancy between the two is likely to be accounted for by our inclusion of service users with mild/moderate learning disabilities.

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<sup>d</sup> These figures have been updated for the present report to define adults as all people aged 18 or over.

If we accept that 145,000 adults have severe or profound learning disabilities, then the Department of Health estimate for adults with mild/moderate learning disabilities is 84% higher than our estimate. This discrepancy is most probably due to the use by the Department of Health of the same prevalence estimate (2.5%) across all age groups. In our estimates we used this prevalence estimate for the 15-24 age group but reduced estimates progressively with age to take into account the increased mortality of people with learning disabilities.<sup>8</sup>

## Are the Numbers of People with Learning Disabilities Changing?

Given that no accurate records are kept of the number of people with learning disabilities in England, it is not possible to determine whether these numbers are changing. A number of factors could lead to a change in the number of people with learning disabilities in England. These include both factors that will influence the future size and composition of the English population (e.g., changes in overall birth rates, migration and mortality), and possible changes in the incidence and prevalence of learning disabilities.

### *General Demographic Change*

Population predictions for England are provided by the Government Actuary's Department (<http://www.gad.gov.uk>). Current predictions suggest that English population will rise from 50.9 million in 2007 to 53.5 million in 2017 and 56.0 million in 2027. However, these overall changes conceal marked changes in the age-structure of the population. The number of young people aged 0-19 is expected to drop from 12.3 million in 2007 to 11.9 million in 2017 (-3%) and then recover to 12.2 million in 2027 (0% change from 2007). The number of adults aged 20-64 is expected to rise from 30.5 million in 2007 to 31.6 million in 2017 (+4%) and 32.0 million in 2027 (+5% change from 2007). The number of older adults aged 65+ is expected to rise from 8.2 million in 2007 to 10.0 million in 2017 (+22%) and 11.8 million in 2027 (+45% change from 2007).

If we assume that there will be no changes in the incidence and prevalence of learning disabilities, these changes in the general population will result in equivalent changes in the population of people with learning disabilities.

### *Potential Changes in the Incidence and Prevalence of Learning Disabilities*

The incidence and prevalence of learning disabilities will be influenced by a range of factors including changes in: rates of exposure to environmental hazards that may cause learning disabilities (e.g., infections, toxins, road traffic accidents, poverty and social deprivation); access to and uptake of screening and selective termination; the life



expectancy of people with learning disabilities; access to and uptake of interventions that may prevent learning disabilities (e.g., phenylalanine free diet, early intervention, potential gene therapies).

In our work for the Department of Health, we argued that three factors are likely to lead to an increase in the age-specific prevalence rates for adults with learning disabilities in England over the next two decades. These are: (1) an increase in proportion of younger English adults who belong to Bangladeshi and Pakistani South Asian minority ethnic communities (among whom evidence suggests there may be a two to three fold increase in the prevalence of more severe learning disability in children and young adults)<sup>9</sup>; (2) increased survival rates among young people with severe and complex disabilities; (3) reduced mortality among older adults with learning disabilities.<sup>4</sup>

By modelling the effects of these changes and combining these with the effects of general demographic change we estimated modest but sustained growth over the next two decades in both the numbers of people with learning disabilities known to learning disability services (11% over the decade 2001-2011, 14% over the two decades 2001-2021) and the estimated 'true' number of people with learning disabilities in England (15% over the decade 2001-2011, 20% over the two decades 2001-2021).<sup>e</sup> These projections were used by the Department of Health to justify the need to review the organisation of social care in England<sup>10</sup> and are broadly consistent with the predictions made in *Valuing People*.<sup>7</sup>

Within the 15-49 age range we predicted very little change in either the number of people with learning disabilities known to learning disability services (4% over the decade 2001-2011, only 0.2% over the two decades 2001-2021) or the estimated 'true' number of people with learning disabilities in England. However, within the 50+ age range we predict very marked increases in both the numbers of people with learning disabilities known to learning disability services (28% over the decade 2001-2011, 48% over the two decades 2001-2021) and in the estimated 'true' number of people with learning disabilities in England (31% over the decade 2001-2011, 53% over the two decades 2001-2021).

Increased demand in the older age groups is of particular significance since older adults with learning disabilities are significantly more likely than younger adults to rely on public funding for supported accommodation. Indeed, we predicted that (assuming the level of rationing of residential support remains constant) public agencies in England will need to provide out-of-home residential support for an additional 12,000 older adults with learning disabilities by 2011 and for an additional 20,000 by 2021.

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<sup>e</sup> The predicted slowing down in the growth of the population of people with learning difficulties reflects the impact of decreased child population in the period up to 2017 and the ageing of the general population

# The Life Experiences of Adults with Learning Disabilities

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In *Valuing People*, the Department of Health made a commitment to 'commission a national survey of people with learning disabilities ... in order to improve our knowledge and provide a stronger baseline against which to evaluate the impact of *Valuing People*'.<sup>7</sup> The results of this survey, which was undertaken in 2003/4, provide the most robust information available on the 'typical' life experiences of people with learning disabilities in England.<sup>11</sup> The full reports of the survey are available from <http://www.ic.nhs.uk/pubs/learndiff2004>. In the following sections we present new analyses of these data that summarise key survey results separately for people with mild/moderate learning disabilities, people with severe learning disabilities and people with profound and multiple learning disabilities.

People were considered to have mild/moderate learning disabilities if they answered most of the interview questions themselves. People were considered to have profound multiple learning disabilities using the definition we developed for CSCI.<sup>12</sup> All other participants were considered to have severe learning disabilities. 2,898 adults with learning disabilities participated in the survey. Of these, 46% were considered to have mild/moderate learning disabilities, 47% were considered to have severe learning disabilities and 7% were considered to have profound multiple learning disabilities.

## Accommodation

Table 1 shows the accommodation arrangements for people with mild/moderate, severe and profound multiple learning disabilities.

	Mild or moderate	Severe	Profound multiple	All people
Private Households				
With parent(s)	48%	61%	60%	55%
With other relative	14%	11%	4%	12%
With partner	6%	<1%	<1%	3%
Alone	7%	2%	0%	4%
Sub-total	74%	74%	65%	74%
Supporting People funded	12%	8%	5%	10%
Residential Care Home	13%	15%	19%	15%
NHS Accommodation	<1%	2%	11%	2%
Total	100%	100%	100%	100%

As can be seen, the majority of people with severe and profound multiple learning disabilities were living with a parent. The majority of people with mild/moderate learning disabilities were living with a parent or other relative. People with more severe learning disabilities were more likely to be living in Residential Care Homes and NHS accommodation.

For people in supported accommodation<sup>f</sup> people were asked whether they had any choice over who they lived with and where they lived. They were also asked about issues relating to privacy (people coming into their room without asking, or when they did not want them to; not being able to be alone with people who come to visit them; people opening their letters without asking them). Table 2 shows the levels of choice and privacy for people with mild/moderate, severe and profound multiple learning disabilities.

	Mild or moderate	Severe	Profound multiple	All people
Some choice over ....				
where they live	63%	38%	12%	47%
who they live with	42%	30%	10%	33%
Privacy in all three areas	73%	62%	49%	65%

The majority of people in supported accommodation had no choice over either who they lived with or where they lived. This was particularly the case for people with more severe learning disabilities. While the majority of people did have acceptable levels of privacy, a substantial minority did not. Again, this was particularly the case for people with more severe learning disabilities.

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<sup>f</sup> This includes all people living in Registered Residential Care Homes, NHS accommodation and accommodation arrangements funded under the *Supporting People* programme.

## Employment

Over four in five (83%) of people with learning disabilities of working age were unemployed. The chances of having any paid employment were, however, much greater for people with less severe learning disabilities. 28% of people with mild/moderate learning disabilities had some form of paid employment compared to 10% of people severe with learning disabilities and 0% of people with profound and multiple learning disabilities. Most of the people who had some form of paid employment were employed for 16 hours or more per week (70% of people with mild/moderate learning disabilities; 57% of people severe with learning disabilities). Information on gross weekly pay was collected for 64% of people who were in paid employment. Pay band for people with mild/moderate and severe learning disabilities are shown in Table 3.

	Mild or moderate	Severe
<£20	12%	31%
£20-£49.99	14%	25%
£50-£99.99	15%	5%
£100-£199.99	39%	26%
£200+	21%	14%
Total	100%	100%

Overall, just 17% of people with mild/moderate learning disabilities and 4% of people severe with learning disabilities who were of working age were reported to be earning more than £100 per week.

Similar associations between support needs and access to employment were also found regarding voluntary work. 7% of mild/moderate learning disabilities had some form of voluntary employment compared to 5% of people severe with learning disabilities and less than 1% of people with profound and multiple learning disabilities.

These figures (17% employed) are, however, higher than those quoted in *The Story So Far ....* the 2004 review of Valuing People (11% employed) and in CSCI estimates (equivalent to 8% employed). The difference is almost certainly due to the government's 'official' figures relating to people with learning disabilities who use learning disability services. The survey also sought to include people with learning disabilities who may not be using learning disability services, a more able group who – as can be seen above – were more likely to be in employment.

## Education & Training

Just over one in three people (36%) were undertaking some form of education or training. This was markedly higher among people with mild/moderate learning disabilities (36%) and people with severe learning disabilities (38%) than among people with profound and multiple learning disabilities (14%).

Just over one in three people (39%) attended a day centre. This was markedly higher among people with profound and multiple learning disabilities (66%) and people with severe learning disabilities (49%) than among people with mild/moderate learning disabilities (24%).

## Hardship & Deprivation

The survey collected information on the types of neighbourhoods that people were living in by linking postcodes to the English Indices of Deprivation.<sup>13</sup> Table 4 shows the percentage of people with mild/moderate, severe and profound multiple learning disabilities living in neighbourhoods that range from the 20% most deprived in England to the 20% most affluent in England. The 'neighbourhoods' used in these indicators all cover a population of approximately 1,500 people. What we would expect to see (if there is no association between learning disabilities and deprivation) is 20% of people living in each quintile.

	Mild or moderate	Severe	Profound multiple	All people
People living in private households				
Quintile 1 (20% most deprived)	31%	27%	33%	29%
Quintile 2	21%	26%	26%	24%
Quintile 3	21%	24%	21%	22%
Quintile 4	18%	13%	16%	15%
Quintile 5 (most affluent)	10%	10%	4%	10%
Total	100%	100%	100%	100%
People living in supported accommodation				
Quintile 1 (20% most deprived)	21%	23%	26%	22%
Quintile 2	24%	20%	29%	23%
Quintile 3	26%	24%	21%	24%
Quintile 4	17%	19%	16%	18%
Quintile 5 (most affluent)	13%	14%	9%	13%
Total	100%	100%	100%	100%

As can be seen, people with learning disabilities living in private households are much more likely to live in areas characterised by high levels of social deprivation.

The survey also used nine modified items from the Millennium Poverty and Social Exclusion Survey<sup>14</sup> to explore levels of material and social hardship faced by people with learning disabilities. Things that people could not afford are listed below.

- A holiday (26% could not afford)
- Going to the pub or club (18%)
- A hobby or sport (17%)
- Going out (16%)
- New clothes (16%)
- New shoes (15%)
- Telephoning friends and family (10%)
- Food (5%)
- Heating (4%)

Table 5 shows the percentage of people with mild/moderate, severe and profound multiple learning disabilities who could afford all of these things, could not afford one of the nine items and could not afford two or more of the nine items.

Table 5: Hardship				
	Mild or moderate	Severe	Profound multiple	All people
People living in private households				
Cannot afford 2 or more items	37%	21%	17%	28%
Cannot afford 1 item	19%	15%	15%	17%
Can afford all items	44%	64%	68%	55%
Total	100%	100%	100%	100%
People living in supported accommodation				
Cannot afford 2 or more items	17%	8%	6%	12%
Cannot afford 1 item	15%	8%	8%	11%
Can afford all items	69%	84%	86%	78%
Total	100%	100%	100%	100%
Note: Private households include people living with their relatives or independently. Supported accommodation includes accommodation provided under the <i>Supporting People</i> programme, by the NHS, and Registered Residential Care Homes.				

As can be seen, people living in private households were much more likely to experience material and social hardship than people in supported accommodation services. Also, people with mild/moderate learning disabilities were much more likely to experience material and social hardship than people with severe or profound and multiple learning disabilities.

## Families, Friends & Relationships

The survey collected information on the frequency of contact people had with their families, friends who themselves had learning disabilities and friends who did not have learning disabilities. Given that the survey used items from the Millennium Poverty and Social Exclusion Survey<sup>14</sup> it is possible to compare these results with those of people who do not have learning disabilities. Table 6 shows the frequency of social contacts for people with mild/moderate, severe and profound multiple learning disabilities and people who do not have learning disabilities.

	Mild or moderate	Severe	Profound multiple	All People with learning disabilities	People without learning disabilities
... members of their family they were not living with	60%	59%	52%	59%	91%
.... friends who have learning disabilities	43%	55%	37%	48%	n/a
... friends who do not have learning disabilities	21%	21%	11%	20%	n/a
.... friends	74%	66%	38%	66%	92%

As can be seen, people with learning disabilities were less likely than people without learning disabilities to have contact with friends and members of their family that they were not living with. The latter is most likely to be due to people with learning disabilities being much more likely to be still living with their families than people without learning disabilities.<sup>11</sup>

## Being Part of the Community

The survey collected information about: what people did in their leisure time; whether they voted and took part in meetings; whether they had been the victim of crime or had been bullied.

### *Leisure & Community Activities*

People were asked whether in the preceding month they had participated in nine specific activities. Table 7 shows the percentage of people with mild/moderate, severe and profound multiple learning disabilities who had participated at least once in these activities.

	Mild or moderate	Severe	Profound multiple	All people
<b>People living in private households</b>				
Been shopping	88%	90%	73%	88%
Visited friends or family	83%	83%	70%	82%
Eaten out in a restaurant, pub or café	61%	75%	50%	67%
Been to a pub or club	55%	60%	36%	56%
Been to the hairdresser	53%	53%	50%	53%
Played sport or gone swimming	39%	48%	36%	43%
Been to the cinema, play or concert	34%	40%	23%	36%
Been to the library	25%	18%	9%	21%
Watch a sporting event	23%	17%	8%	20%
Done none or only one of these things	4%	4%	17%	5%
<b>People living in supported accommodation</b>				
Been shopping	91%	91%	81%	90%
Visited friends or family	73%	61%	44%	65%
Eaten out in a restaurant, pub or café	76%	83%	79%	80%
Been to a pub or club	70%	80%	66%	75%
Been to the hairdresser	71%	76%	75%	74%
Played sport or gone swimming	37%	38%	33%	38%
Been to the cinema, play or concert	47%	51%	30%	47%
Been to the library	30%	19%	6%	23%
Watch a sporting event	22%	18%	8%	19%
Done none or only one of these things	3%	4%	9%	4%

As can be seen, people with profound and multiple learning disabilities were notably less likely to participate in a range of activities than people with mild/moderate or severe learning disabilities. One in twenty people with profound and multiple learning disabilities living in private households had not done any of the things listed in the preceding month.



## *Voting*

Less than one in three people with learning disabilities (31%) reported that they voted in the 2001 general election. Voting was higher among people with mild/moderate learning disabilities (42%) than among people with severe learning disabilities (27%) and people with profound and multiple learning disabilities (4%). In the 2003 Home Office Citizenship Survey 72% of people said that they voted in the 2001 general election. In the Millennium Poverty and Social Exclusion Survey, 73% of people said that they voted in the 2001 general election. (The actual turnout for the election was 59%.)

## *Attending Self-Advocacy Meetings*

Just over one in four people with learning disabilities (28%) reported having attended a self-advocacy meeting. This was higher among people with mild/moderate learning disabilities and people with severe learning disabilities (both 29%) than among people with profound and multiple learning disabilities (15%).

## *Crime & Bullying*

Participants were asked whether in the last year anybody had been rude or offensive to them because they have a learning disability. Nearly one in three people (32%) said someone had been rude to them. This was higher among people with mild/moderate learning disabilities (33%) and people with severe learning disabilities (31%) than among people with profound and multiple learning disabilities (24%).

Overall, the kinds of people who were most likely to be rude or offensive to them because they have a learning disability were

- A stranger (63%)
- Someone they know/a friend (14%)
- Someone at the day centre (9%)
- Someone they work with (8%)
- Someone they lived with (8%)
- Someone at college (4%)
- Paid support workers (4%)

Overall, nearly one in ten people (9%) said they had been the victim of crime in the last year. This was higher among people with mild/moderate learning disabilities (12%) and people with severe learning disabilities (8%) than among people with profound and multiple learning disabilities (4%). This is much less than the chances of being a victim of crime as reported in the general population in the 2003/4 in the British Crime Survey (26%).

A small number of people with learning disabilities (2.8%) reported having been assaulted during the past year. This was higher among people with mild/moderate learning disabilities (3.2%) and people with severe learning disabilities (2.4%) than among people with profound and multiple

learning disabilities (0%). This is slightly higher than the chances of being assaulted as reported in the general population in the 2003/4 in the British Crime Survey (2.2%).

## Health & Well-Being

The survey collected information about smoking and exercise, important health behaviours that are likely to have an impact of people's future health.

- Just under one in five (19%) reported that they smoked cigarettes. This was higher among people with mild/moderate learning disabilities (30%) than people with severe learning disabilities (11%) and people with profound and multiple learning disabilities (4%). Rates of smoking were also higher among people living in private households. For example, 35% of people with mild/moderate learning disabilities living in private households smoked compared with 17% of people with mild/moderate learning disabilities living in supported accommodation.
- One in five (20%) reported that they exercised three or more times a week. This was higher among people with mild/moderate learning disabilities (23%) than people with severe learning disabilities (18%) and people with profound and multiple learning disabilities (9%). Rates of exercising were also higher among people living in private households. For example, 26% of people with mild/moderate learning disabilities living in private households exercised three or more times a week with 16% of people with mild/moderate learning disabilities living in supported accommodation.

The survey also collected information on use of primary care health services. Table 8 shows the percentage of people mild/moderate, severe and profound multiple learning disabilities who had used various types of health services.

	Mild or moderate	Severe	Profound multiple	All people
Registered with GP	99%	100%	99%	99%
Been to GP in last year	76%	80%	80%	78%
Registered with dentist	77%	85%	83%	82%
Been to dentist in last year	67%	75%	77%	72%
Eyes tested in last year	51%	55%	41%	52%
Hearing tested in last year	17%	25%	23%	21%
Had cervical smear (of women)	42%	16%	5%	27%
Had mammogram (of women)	27%	22%	19%	24%

The rates of use of all health services were higher for people living in supported accommodation services than for people living in private households.

## National Datasets

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The national survey concerning the life experiences of adults with learning disabilities (see above and <sup>10</sup>) provides the most comprehensive recent national snapshot of the lives of people with learning disabilities. While there are several sources of national statistical information relevant to people with learning disabilities collected for Government departments, they largely concern aspects of service activity rather than people's life experiences<sup>1</sup>. A recent study for the Department of Health comprehensively trawled the available national statistics concerning people with learning disabilities in England<sup>1</sup>, and a table of potential data sources found in that study is presented below in Table 9. Some of the more relevant national statistics from this table are reported here using the latest available statistics (typically for 2005-2006), with comparisons to 2000-2001 where possible.

Table 9: National statistics potentially relevant to people with learning disabilities in England identified in Hatton et al. (2005)<sup>1</sup>.

Reference Number	DATA SOURCE/COLLECTED BY	Collection Frequency			
		Annual	Quarter	Month	Other
<b>DEPARTMENT OF HEALTH</b>					
1	Private Nursing Homes, Hospitals and Clinics	√			
2	Community Care Statistics (Supported Residents – Adults)	√			
3	Community Care Statistics (RAP – Referrals, Assessments and Packages of Care)	√			
4	Personal Social Services Staff of Social Services Departments	√			
5	Performance Assessment Framework (PAF)	√			
6	Inpatients formally detained in hospitals	√			
7	Community Learning Disability Nursing	√			
8	Hospital Episode Statistics	√			
9	Personal Social Services Expenditure and Unit Cost	√			
10	Inpatient, Day Care and Residential Beds	√			
11	People Registered as Blind and Partially Sighted				√
12	Waiting Time Performance		√		
13	Health Care Providers and Waiting Times(Health Authorities and NHS Trusts)		√		
14	Head Quarters/Regional Offices and Waiting Times		√		
15	Outpatient Activity and Attendance		√		
16	Waiting Times		√		
17	Primary Care Trusts/Strategic Health Authorities and Waiting Times		√		
18	Health Authorities and Waiting Times		√		
19	NHS Trusts/Primary Care Trusts and Waiting Times		√		
20	HQ and Regional Offices Waiting Times (NHS Trusts and Primary Care Trusts)		√		
<b>DEPARTMENT FOR FURTHER EDUCATION AND SKILLS</b>					
21	Pupil Level Annual School Census (PLASC)	√			
22	Special Educational Needs (SEN)	√			
23	Connexions Partnership		√		
<b>DEPARTMENT FOR WORK AND PENSIONS</b>					
24	Incapacity Benefit and Severe Disability Allowance		√		
25	Disability Living Allowance		√		
26	Attendance Allowance		√		
27	Carers Allowance		√		

Reference Number	DATA SOURCE/COLLECTED BY	Collection Frequency			
		Annual	Quarter	Month	Other
28	Benefits Data System				√
29	Labour Market System			√	
30	Workstep			√	
31	Work Prep.			√	
32	New Deal for Disabled People			√	
33	Access to Work			√	
34	Social Fund Policy, Budget and Management Information System (PBMIS)			√	
<b>OFFICE OF THE DEPUTY PRIME MINISTER</b>					
35	Disabled Facilities Grants/Renewal Grants	√			
36	Supporting People Client Record Form	√			
37	P1E – Homelessness statistics	√			
<b>OTHER ORGANISATIONS</b>					
38	Delivery Improvement Statement (DIS) - Commission for Social Care Inspection (CSCI)	√			
39	Higher Education Student Statistics - HESA	√			
40	Housing Associations & Independent Organization Schemes - Housing Corporation	√			
41	RSR/Housing Association Stock Census and CORE - Housing Corporation	√			
42	Continuous Recording of Lettings (CORE) – National Housing Federation		√		
43	Individualised Learner Records - Learning and Skills Council (LSC)	√			
44	Personal Social Services (Estimates) - CIPFA	√			
45	Electronic Patient Records – GRPD	√			
46	Independent Living Fund		√		
47	Registration and Inspection Database - Commission for Social Care Inspection (CSCI)			√	
48	Learners with Learning Difficulties and/or Disabilities Placements Process - Learning and Skills Council			√	

## Accommodation

Unless otherwise stated, all figures refer to services in England.

### *NHS and Independent Sector Hospitals*

According to Hospital Activity Statistics (Table 9 ref 10)<sup>14</sup>, in 2005-2006 there were 3,927 available NHS overnight beds in England for people with learning disabilities (down 38% from 6,316 available beds in 2000-2001), of which 3,291 were occupied. In total, these beds constitute 2.2% of the total number of overnight beds available in the NHS. Specific types of bed included:

- Short-stay beds for children (208 available, 134 occupied)
- Long-stay beds for children (26 available, 21 occupied)
- Short-stay beds for other ages (1,188 available, 938 occupied)
- Long-stay beds for other ages (1,978 available, 1,696 occupied)
- Secure beds for other ages (526 available, 502 occupied)

The number of available and occupied beds in all categories dropped from 2000-2001 to 2005-2006, except for NHS secure beds which have increased by 22% from 431 beds (availability) and 23% from 408 beds (occupancy) over this time period.

These figures do not exactly tally with the number of NHS residential beds for people with learning disabilities also reported in the Hospital Activity Statistics. Here, 2,494 NHS residential beds were reported as being available in 2005-2006, down from 3,703 in 2000-2001. These beds constitute 56% of all NHS residential care beds in England. Of these 2,494 available beds, 2,273 were occupied in 2005-2006, an occupancy rate of 91%.

In 2006, the Mental Health Act Commission conducted Count Me In, a comprehensive census of all mental health and learning disabilities inpatients in NHS and independent sector hospital providers in England and Wales<sup>15</sup>. This was too recent to be included in the scoping study for the Department of Health, and hence is not included in Table 9. Within English services self-identified as providers for people with learning disabilities, 4,435 people were identified, 3,505 in NHS services and 930 in independent sector services. However, it is important to note that these figures do not represent the total number of people with learning disabilities in such hospitals:

- Of the 4,435 people in learning disability provider services, 10.7% (475 people) were identified as not having a learning disability or autistic spectrum disorder.
- In mental health provider services, 748 people were identified as having learning disabilities and 142 as having an autistic spectrum disorder, 3% of the total number of inpatients in mental health service providers.

The learning disability provider inpatient population was predominantly White (4,180 people; 90.3%) and male (3,304 people; 65.8%), although particularly high admission rates were reported for Mixed White/Black

Caribbean, Black Caribbean and Other Black ethnic groups and particularly low admission rates were reported for White Other, Asian and Chinese ethnic groups. Most people were aged 25-49 (2,619 people; 56.8%), with a small number aged under 18 (110 people; 2.5%).

At the time of the Count Me In census, most people in learning disability provider services had an informal legal status (2,955 people; 63.5%), with the remainder largely detained under Section 3 (934 people; 20.7%), Section 37/41 (301 people; 6.7%) or Section 37 (253 people; 5.7%). Most people (2,705 people; 58.3%) were also deemed incapable of giving consent, including 74% of people with an informal legal status (2,064 people). Most people had been resident in their service for a considerable length of time: 10.3% (462 people) less than 30 days; 13.0% (600 people) 1-6 months; 9.1% (417 people) 6-12 months; 30.6% (1,394 people) 1-5 years; 35.4% (1,665 people) greater than 5 years.

Most people were reported to be in general services with regard to security (2,741 people; 58.1%), with a further 23.4% (1,037 people) in low secure services, 17.1% (768 people) in medium secure services and only 1.4% (63 people) in high secure services. People were resident in a wide range of types of service, most commonly 'long stay - greater than 1 year' (1,631 people; 34.4%); assessment and treatment units (1,246 people; 27.1%) and NHS campuses (480 people; 10.8%). Other service types included short stay – less than 1 year (305 people; 6.5%); respite (190 people; 4.2%); rehabilitation (156 people; 3.5%); 'old long stay' (153 people; 3.1%); and high dependency units (108 people; 2.4%).

Few people had experienced at least one episode of seclusion in their current inpatient spell or in the last three months (165 people; 3.7%), although more people had experienced at least one episode of restraint (1,038 people; 22.7%, including 218 people (4.8%) experiencing 11 or more restraint episodes), at least one episode of self-harm (698 people; 14.9%) or at least one accident (866 people; 18.9%).

### *Council Supported Residents*

All councils with social service responsibilities (CSSRs) in England provide annual returns concerning the number of adults they are supporting in residential accommodation (Table 9 ref 2)<sup>16</sup>. Figures broken down by social care group are available for adults aged 18-64 (there are an additional 200,055 council supported residents aged 65+, but these are not broken down by social care group).

At 31 March 2006, there were a total of 35,260 council supported residents with learning disabilities aged 18-64 (60% of all council supported resident adults aged 18-64). In this dataset the 2006 figures are not directly comparable to figures for 2001, as from 2003 onwards people with preserved rights have been added to the figures. However, the 2006 figure of 35,260 is a decrease from the directly comparable 2003 figure of 36,320 people. More specifically, in 2006 there were:

- 3,200 people in council staffed residences (down from 4,505 people in 2003)

- 28,080 people in independent sector registered residential homes (down from 28,940 people in 2003)
- 1,840 people in independent sector nursing homes (virtually unchanged from 1,855 people in 2003)
- 2,140 people in unstaffed or other types of home (up from 1,020 people in 2003)

It is important to note that there were also 2,225 adults with learning disabilities in adult placements at 31 March 2006. Furthermore, at 31 March 2006 there were 11,345 adults with learning disabilities aged 18-64 supported by councils and living outside the boundaries of their 'home' council, 57% of all council-supported residents aged 18-64 living out of area. At 31 March 2006 there were an additional 28,945 council-supported residents aged 65 or over living out of area, although these are not disaggregated by client group.

Community Care Statistics: Referrals, Assessments and Packages of Care for 2005-2006 (Table 9 ref 3)<sup>17</sup> report figures using slightly different categories from the same set of reporting councils, and reporting on all adult ages from 18 upwards. Again the figures for 2005-2006 are not directly comparable to 2000-2001 figures due to the addition of people with preserved rights, but comparable figures for 2002-2003 are available:

- 3,600 adults in local authority residential care (3,000 aged 18-64; 600 aged 65+) – down from 4,700 adults in 2002-2003 (3,900 aged 18-64; 700 aged 65+);
- 36,000 people in independent sector residential care (32,000 aged 18-64; 4,500 aged 65+) – down from 37,000 adults in 2002-2003 (34,000 aged 18-64; 3,900 aged 65+);
- 4,000 people in nursing care (2,600 aged 18-64; 1,300 aged 65+) – up from 3,300 in 2002-2003 (2,500 aged 18-64; 900 aged 65+).

Despite this decrease in local authority residential care places, the number of residential care staff directly employed by social services departments in England to work with people with learning disabilities has barely changed from 2001 to 2006 (Table 9 ref 4)<sup>19</sup>:

- 2,100 WTE social services staff in residential care for children with learning disabilities in 2006 (unchanged from 2001)
- 10,200 WTE social services staff in residential care for adults with learning disabilities in 2006 (down from 10,500 in 2001).

Personal Social Services Expenditure and Unit Costs for 2005-2006 (Table 9 ref 9)<sup>18</sup> reports the following unit costs for residential services for adults with learning disabilities in England:

- Nursing care unit cost £843 per person per week (up 12.4% from £750 in 2000-2001)
- Residential care unit cost £895 per person per week (up 26.8% from £706 in 2000-2001).

The rise in nursing care unit costs is roughly in line with general inflation over this time period, but the rise in residential care unit costs is considerably above general inflation.



Gross personal social services expenditure on residential services for adults with learning disabilities aged under 65 includes:

- £77.1 million on nursing home places (up 120% from £35.1 million in 2000-2001)
- £1,393.6 million on residential care home places (up 59% from £877.6 million in 2000-2001)
- £191.2 million on supported/other residential places (up 86% from £102.8 million in 2000-2001).

## Community Services

Community Care Statistics: Referral, Assessment and Packages of Care for 2005 -2006 (Table 9 ref 3)<sup>17</sup> reports several statistics concerning community services for people with learning disabilities, largely provided by councils with social service responsibilities.

### *Assessments and reviews*

In 2005-2006, 8,000 adults with learning disabilities aged 18+ were reported as new clients receiving an assessment (1.2% of the total number of 651,000 new adults receiving a social services assessment in 2005-2006). For 2,100 of these new clients (27.6% of the 8,000 adults with learning disabilities) it took more than 3 months from first contact to a completed assessment, compared to 9% of all adults who received a social services assessment in 2005-2006. Of these 8,000 new clients, 4,800 (60%) were reported to have received (or were intended to receive) some new service as a result of the assessment.

In 2005-2006, an estimated 85,000 adults with learning disabilities aged 18+ were reported as existing clients who had completed reviews in the time period.

In total, social services departments spent £205.4 million on assessment and care management for adults with learning disabilities aged under 65 in 2005-2006 (Table 9 ref 9)<sup>18</sup> (up 96% from £104.8 million in 2000-2001).

### *Community Services*

In total, it was reported that 134,000 adults with learning disabilities aged 18+ received some form of service from the local authority in 2005-2006 (up 23% from 109,000 adults in 2000-2001), including 103,000 receiving community-based services (up 13% from 91,000 adults in 2000-2001).

More specifically:

- 27,000 people received home care (up 197% from 9,100 adults in 2000-2001)
- 58,000 people received day care (unchanged from 2000-2001). The number of WTE social services staff in day centres is also virtually unchanged, from 13,300 in 2001 to 13,200 in 2006<sup>19</sup>.
- 1,100 people received meals (down 48% from 2,100 adults in 2000-2001)

- 12,000 people received overnight respite not in the client's home (up 9% from 11,000 adults in 2000-2001)
- 5,800 people received short-term residential services (not respite) (up 18% from 4,900 adults in 2000-2001)
- 5,500 people received direct payments (up 2,650% from 200 adults in 2000-2001)
- 38,000 people received professional support (up 52% from 25,000 adults in 2000-2001)<sup>9</sup>
- 6,000 people received equipment and/or adaptations (up 67% from 3,600 adults in 2000-2001)
- 17,000 people received an 'other' type of service (up 49% from 8,700 adults in 2000-2001).

It is important to note that the 2000-2001 figures include a transport category (received by 12,000 adults with learning disabilities) that is not included in the 2005-2006 figures.

All community-based services were predominantly received by adults with learning disabilities aged 18-64 rather than aged 65+. Of the population of 134,000 adults with learning disabilities receiving services, 87.3% (117,000 people) were White, 3.2% (4,300 people) Asian/Asian British, 2.4% (3,200 people) Black/Black British, 0.8% (1,000 people) Mixed, 0.8% (1,000 people) Chinese/Other, and 3.0% (4,000 people) not known. The last category presents the biggest contrast with 2000-2001 data, where the ethnicity of 21% of people using services (23,000 people) was not known.

The Commission for Social Care Inspection largely uses collated figures from existing national data sources to produce a Data Analysis Tool, a suite of performance indicators concerning local authority services for people with learning disabilities (Table 9 ref 38)<sup>20</sup>. From this dataset, in 2005-2006 2.8 adults with learning disabilities aged 18-64 per 1,000 local population were helped to live at home, a slight increase from 2.5 per 1,000 in 2000-2001.

Personal Social Services Expenditure and Unit Costs for 2005-2006 (Table 9 ref 9)<sup>18</sup> reports the following unit costs for selected community-based services for adults with learning disabilities in England:

- Home care unit costs £346 per person per week (up 61.7% from £214 in 2000-2001)
- Direct payments £179 per person per week (up 11.9% from £160 in 2000-2001)
- Day care unit costs £277 per person per week (up 25.3% from £221 in 2000-2001). As the unit cost for a ½ day session is given as £34, it can be assumed that adults with learning disabilities using day care receive an average 8.1 sessions per week day care.

Direct payment unit costs seem pegged to general inflation; it is unclear whether increases in home care and day care unit costs are due to cost increases or increases in the scale of services offered to individuals.

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<sup>9</sup> This includes any professional activity undertaken by the care manager, social worker or other professional staff, such as Occupational Therapists, that is beyond the process of care management

Gross personal social services expenditure on community-based services for adults with learning disabilities aged under 65 (Table 9 ref 9)<sup>18</sup> includes:

- £288.1 million on home care (up 160% from £110.9 million in 2000-2001)
- £620.5 million on day care (up 37% from £451.4 million in 2000-2001)
- £1.3 million on meals (up 30% from £1.0 million in 2000-2001)
- £42.2 million on direct payments (up 2,538% from £1.6 million in 2000-2001)
- £0.8 million on equipment and/or adaptations (up 13% from £0.7 million in 2000-2001)
- £93.5 million on other services (up 41% from £66.3 million in 2000-2001).

In total, including all components of social services expenditure for adults with learning disabilities aged under 65, the gross total personal social expenditure in 2005-2006 was £2,914.6 million (15.6% of all personal social services expenditure). Including Supporting People expenditure, the total rises to £3,110.3 million, 23.4% of all personal social services expenditure including Supporting People.

### *Carers*

In 2005-2006, 31,000 assessments/reviews involving carers of adults with learning disabilities were completed (9.1% of the total number of completed carer assessments/reviews), with 3,000 carers declining an assessment or review. Of these completed assessments/reviews, 20% were conducted with a carer where the adult with learning disabilities was aged 65+. From these reviews, 10,000 carers (32.2%) received some information and 16,000 (51.6%) received some form of service (Table 9 ref 3).

The Commission for Social Care Inspection Data Analysis Tool (Table 9 ref 38)<sup>20</sup> states that in 2005-2006 councils spent an average £142,200 on helping an average 238 carers of people with learning disabilities.

### Health Services

Hospital Activity Statistics (Table 9 ref 15)<sup>14</sup> report that, from January to March 2007, 438 referrals were made by GPs and 965 referrals from other sources for an outpatient hospital appointment with a learning disability specialist.

Hospital Episode Statistics (Table 9 ref 8)<sup>21</sup> report that in 2005-2006, there were 55,574 attended outpatient appointments with clinical specialists with a primary expertise in learning disabilities, down from 81,241 in 2000-2001. In total there were 10,945 admissions to inpatient NHS services by people with learning disabilities in 2005-2006 (although this includes admissions to NHS residential care), including 1,456 emergency admissions.

Council statistics collated by the Commission for Social Care Inspection (Table 9 ref 38)<sup>20</sup> suggest that in 2006 an average of 31 adults with learning disabilities per council were referred to drug treatment programmes.

## Advocacy

According to figures collated by the Commission for Social Care Inspection<sup>20</sup> (Table 9 ref 38), in 2005-2006 councils spent an average £95.00 on advocacy for people with learning disabilities per person with learning disabilities known to the council, up from £59.89 per person in 2000-2001.

## Employment

According to figures collated by the Commission for Social Care Inspection<sup>20</sup> (Table 9 ref 38), 0.4 adults with learning disabilities of working age were in paid employment per 1,000 of the local working age population. This is equivalent to approximately 12,500 adults with a learning disability of working age (or 8% of the estimated total population of adults with a learning disability of working age). A similar number (0.4 per 1,000) were in voluntary employment. Raw numbers are not provided in this dataset.

## Benefits

The Department for Work and Pensions<sup>22</sup> provides quarterly information on Attendance Allowance (Table 9 ref 26) and Disabled Living Allowance (DLA) (Table 9 ref 25) for adults with learning difficulties in Great Britain. In the quarter ending November 2006, 3,100 people were claiming Attendance Allowance (0.2% of the total number of claimants), down from 3,800 in the same quarter in 2002.

In the quarter ending November 2006, 263,050 adults with learning difficulties were receiving Disabled Living Allowance (9.2% of the total number of claimants) at an average weekly rate of £54.87, up from 223,420 people in the same period in 2002 (average weekly rate £47.95). A total of 2,390 people with learning difficulties were eligible for DLA but their payments were suspended at the time (e.g. the person was in hospital).

DLA consists of two components which are assessed and paid separately, a Care Award (paid at higher, middle and lower rates) and a Mobility Award (paid at higher and lower rates). In the publicly available national statistics figures for people with learning difficulties cannot be disaggregated by both Care Award and Mobility Award levels simultaneously. This means that figures by level of Care Award, for

example, report the average *total* DLA amount (i.e. including both Care Award and Mobility Award components) received by people at different levels of Care Award – this is why people at the ‘nil’ rate of Care Award are still receiving some DLA (for the Mobility Award component).

In terms of Care Award Type, there were 60,140 people with learning difficulties currently claiming DLA at the higher rate (average £88.12 per week), 123,580 people claiming DLA at the middle rate (average £57.36 per week), 41,590 people claiming DLA at the lower rate (average £29.62 per week) and 37,740 people claiming DLA at the nil rate (average £21.57 per week).

In terms of Mobility Award Rate, there were 37,250 people with learning difficulties claiming DLA at the higher rate (average £89.95 per week), 196,320 people claiming DLA at the lower rate (average £50.91 per week) and 29,490 people claiming DLA at the nil rate (average £36.93 per week).

## Variation

As highlighted in Rob Greig’s overview report of the first four years of Valuing People<sup>26</sup>, almost all national statistics presenting data broken down by region or locality show large geographical variations. These variations may partly be accounted for factors such as:

- Inconsistencies or errors in the data provided by local agencies
- Variations in the size, population and socio-economic circumstances of localities
- Historical patterns of service provision influencing the current location of people with learning disabilities
- Variations in eligibility and assessment criteria across localities

However, these factors taken together seem unlikely to explain the magnitude of the geographical variation that exists across localities in England. To account for differences in locality population numbers and eligibility criteria, the Commission for Social Care Inspection Data Analysis Tool (Table 9 ref 38)<sup>20</sup> contains several indicators that are expressed as a proportion of the total local population of the appropriate age – these give a useful perspective on cross-council variation. Although such variations can be found on almost any indicator, some examples are presented below.

- Council spending on advocacy for adults with learning disabilities – the top quartile of councils spend twice as much per head of local population than the bottom quartile of councils.
- The number of adults with learning disabilities in paid work – in the top quartile of councils the paid employment rate was 2.5 times that of the bottom quartile of councils.
- Adults with learning disabilities were more than twice as likely to have regular short-term breaks written into their care plan in the top quartile of councils compared to the bottom quartile of councils.

## Measuring Outcomes

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This section of the report briefly outlines some of the major issues involved in developing national information systems based on outcomes rather than resources or service activity. A set of 15 performance indicators for people with learning disabilities proposed by the CSCI Learning Disability Group (see reference 25 for details) is also briefly outlined, together with some additional indicators proposed by MENCAP.

### Evaluating The Impact Of Valuing People

As mentioned earlier, the Department of Health recently commissioned a research project with the overall objective of helping the Government to develop ways of evaluating the impact of *Valuing People* at a national level. The project had three phases:

**Phase 1:** To locate and map existing national data sources relevant to services for people with learning disabilities, and to assess their potential usefulness for evaluating the impact of *Valuing People*<sup>1</sup>.

**Phase 2:** To work with people with learning disabilities, family members and other stakeholders to identify what information should be collected at a national level to enable the Government to evaluate the impact of *Valuing People*<sup>23, 24</sup>.

**Phase 3:** To develop practical ways of collecting, analysing and reporting national information to enable the Government to evaluate the impact of *Valuing People*<sup>25</sup>.

Drawing from the findings of the project as a whole, five major conclusions were drawn:

1. People with learning disabilities, family carers and existing policies all emphasise the importance of outcomes (whether people's life experiences reach generally accepted standards of acceptability and decency, and whether people are in control of their lives and achieving their aspirations).
2. Existing information collected nationally concerning people with learning disabilities does not reflect the importance of outcomes, being largely focused on the resources and activities of particular services.
3. A major shift will be required in both the type of information collected and the methods used to collect it if outcomes are to be placed at the heart of national data collection.
4. The methods and technology required to collect outcome information from people with learning disabilities and their families already exist; the major challenge is to translate existing knowledge into feasible methods for collecting national information.

5. People with learning disabilities and family carers need to have a much bigger role in both deciding the priorities for information collection and accessing this information.

On the basis of these conclusions, the project report proposes five principles for the development of national performance indicators concerning people with learning disabilities:

- 1) National statistics and performance indicators should place a much greater emphasis on outcomes (the life experiences of people with learning disabilities) rather than on resources or service activities.
- 2) People with learning disabilities and family carers should be given a central role in shaping the outcomes agenda, particularly in terms of which types of information should be collected, and should be able to access and use the information obtained.
- 3) Data collection systems should be designed around the totality of the lived experience of people with learning disabilities rather than producing aggregate statistics concerning the activities of specific services.
- 4) National statistics should reflect current Government policies and their associated objectives.
- 5) National statistics should be able to document potential areas of inequality; between people with learning disabilities and the general population; and within the population of people with learning disabilities.

The report developed an outcomes framework based on these five principles, as well as taking into account issues of feasibility, cost-effectiveness and the burden of data collection on service agencies. For the purposes of performance indicator development, two levels of outcome measurement are particularly pertinent:

**Level 1: General outcomes** that are about the totality of a person's life and that are unlikely to be solely and directly attributable to the impact of any particular service/support agency (or indeed, all services/support agencies combined), such as citizenship. These general outcomes are, however, crucial for evaluating the effectiveness of national policy and for assessing inequalities between people with learning disabilities and the general population. We suggest that these types of outcome indicators are collected on a regular basis (for example, every three or five years) using national survey methodologies that would recruit nationally representative samples (including people with learning disabilities not known to services).

**Level 2: Outcomes that can be directly attributable to service/support agency activities** (e.g. choice and control within a self-directed support process). In addition to the general outcome indicators outlined above, it is also vital to collect information on

outcomes that are directly attributable to the activities of services and support agencies. Such outcome indicators will be core performance indicators for government and inspectorate agencies, and will be collected in sufficient numbers at a local level to enable comparisons between localities. Several issues need to be considered when developing such a set of outcome indicators:

- A small number of these service-level outcome indicators may also be appropriately collected in the regular national survey proposed above, if they are crucial to general policy directions.
- Inspectorates and government agencies may wish to consider if they need to distinguish between outcome indicators that concern minimum standards and outcome indicators that will reflect continuing improvement or developmental standards.
- Inspectorates and other government agencies will need to consider which outcome indicators can be used consistently across groups of people using services, and which outcome indicators may need to be developed as additional modules for specific groups.
- Information concerning service-level outcomes will need to be collected directly from people with learning disabilities and family members.

This has a number of implications for information collection systems:

- Current local information collection systems will need to be reconfigured to allow for the collection of outcome information directly from service users and family members, possibly with some transitional additional costs concerning training and information system development.
- Information collection systems will need to ensure that performance indicators based on service-level outcome indicators can be broken down into sub-groups potentially associated with inequalities in the experience of services, such as gender, age, ethnicity, support needs, socio-economic position etc.
- The cost-effectiveness of collecting outcome information directly from service users and family members can be maximised in the following ways:
  - Some outcome indicators can be collected on random samples of service users, rather than entire local communities of service users.
  - Some outcome indicators may be able to be built into routine service assessment or review systems.
  - A single comprehensive set of service-level outcome indicators across all service domains should be collected from service users and families, with the resulting information shared across all relevant government departments and inspectorates. This would reduce the burden of information collection on local agencies and service users or family members, and would provide a comprehensive picture of the use of mainstream supports as well as particular specialist services.

Technical and methodological issues concerning the collection of reliable and valid information from people with learning disabilities (and proxy informants where necessary) will also need to be considered. Many of



these issues have been addressed by researchers working with people with learning disabilities, although more work needs to be done. The issues identified below may also be relevant to some other groups of people using services.

- Getting reliable and valid information from people with learning disabilities. Issues here involve assessing the capacity of the person to answer questions and ensuring questions are accessible to the maximum number of people with learning disabilities.
- The role of proxy respondents in reporting the life experiences of a person with learning disabilities. What sort of information can be provided in a reliable and valid way by proxies, and when should information be gained from proxies?
- Gaining information from people with learning disabilities (and possibly some proxy informants) is likely to involve face-to-face interviews rather than questionnaires, with training and resource implications.
- Ensuring that performance indicators and associated questions are valid cross-culturally.
- Identification issues. Given likely differences in eligibility criteria across areas, and the probability that some people with learning disabilities will not be in contact with services, it will be necessary to be able to quickly and reliably assess if a person has a learning disability.

## Proposed Performance Indicators

In 2006, a Learning Disability Group set up by the Commission for Social Care Inspection recommended 15 performance indicators concerning people with learning disabilities<sup>25</sup>. Due to bigger changes in inspection regimes and organizational changes involving CSCI, these proposals have not been taken forward by CSCI. They also represent something of a halfway house in terms of outcome measurement, in that they still rely on aggregated data that is largely about service activity rather than outcome information collected directly from people using services. However, they do represent a set of performance indicators that were felt to be potentially robust and feasible by a group including local authority information collection experts. Table 11 below presents these proposed performance indicators, with a brief description of any current regularly updated national information relevant to each performance indicator. It is important to note that none of the national indicators currently collected provide data broken down by level of disability.

Table 11: Performance indicators proposed by the CSCI Learning Disability Group (all the indicators in the table are for people with learning disabilities)

<b>PI Domain</b>	<b>Additional PI</b>	<b>Current National Information</b>
Improved health and emotional well-being	Number of people with completed health action plans	Better Metrics <sup>27</sup> , sponsored by the Healthcare Commission, has a voluntary performance indicator on completed health action plans.
Improved quality of life	Number of people supported to live in the community	Number of adults aged 18-64 'helped to live at home' available in CSCI Data Analysis Tool (Table 9 ref 38) <sup>20</sup> . In 2005-2006 2.8 adults with learning disabilities aged 18-64 per 1,000 local population were helped to live at home.
	Number of carers receiving support from the council	Total number of carers across all groups receiving support in CSCI Data Analysis Tool (Table 9 ref 38) <sup>20</sup> , not yet broken down into carers of people with learning disabilities.
	Number of carers receiving short term breaks and emergency support	CSCI Data Analysis Tool (Table 9 ref 38) <sup>20</sup> collects this information by service users, not carers.
	Number of people	Detailed information on housing

	<p>living in each of the following types of housing:</p> <p>Living in housing owned or rented by a family member aged under 65</p> <p>Living in housing owned or rented by a family member aged over 65</p> <p>Homeowner</p> <p>Shared ownership</p> <p>Tenant in self-contained accommodation</p> <p>Tenant in shared accommodation (3 people or more)</p> <p>Supported lodgings or adult placement</p> <p>Residential care home</p> <p>Nursing home</p> <p>NHS residential accommodation</p> <p>Other</p> <p>Number of people living as tenants or homeowners</p> <p>Number of people living in residential services</p> <p>Number of people living outside the local authority boundary</p>	<p>type not yet available. Information for 2005-2006 is available for:</p> <p>Council supported residents aged 18-64 (Table 9 ref 2<sup>16</sup>; total 35,260) in:</p> <p>Council staffed residences (3,200)</p> <p>Independent sector registered residential care homes (28,080)</p> <p>Independent sector nursing homes (1,840)</p> <p>Unstaffed/other (2,140)</p> <p>Adult placements (2,225)</p> <p>NHS residential beds (Table 9 ref 10<sup>14</sup>): 2,273 occupied; 2,494 available</p> <p>No information available</p> <p>No information available</p> <p>Available for council-supported residents (not NHS or other) (Table 9 ref 2<sup>16</sup>): 11,345 adults age 18-64 in 2005-2006</p>
Making a positive contribution	Number of people doing voluntary work and work experience	Available data for adults aged 18-64 known to council (Table 9 ref 38 <sup>20</sup> ) for voluntary work only: 0.4 per 1,000 general population in 2005-2006
Choice and control	Number of people receiving a direct payment	Available data for adults aged 18-64 (Table ref 3 <sup>17</sup> ): 5,500 people received direct payments in 2005-2006
	Number of people	No available data

	receiving another form of individual budget  Local authority spend on advocacy	Available data (Table 9 ref 38 <sup>20</sup> ): £95 per person aged 18-64 known to the council in 2005-2006
Freedom from discrimination	Number of reports of harassment and abuse against people with learning disabilities	No available data
Economic well-being	Number of people in full-time employment  Number of people in part-time employment	Only available data on adults aged 18-64 known to councils in paid employment (not divided into full-time vs part-time) (Table 9 ref 38 <sup>20</sup> ): 0.4 adults per 1,000 general population in paid employment in 2005-2006

MENCAP has proposed an additional set of performance indicators to supplement the PIs proposed by the CSCI Group. Table 12 below presents these proposed performance indicators, with a brief description of any current regularly updated national information relevant to each performance indicator. As Table 12 shows, there are currently few regularly updated national datasets that provide the information required by the 15 proposed performance indicators.

Table 12: Additional performance indicators proposed by MENCAP

<b>PI Domain</b>	<b>Additional PI</b>	<b>Current National Information</b>
Meaningful day time activities	Numbers getting day services	National information available annually on number of adults with learning disabilities using social services-funded day care (Table 9 ref 3) <sup>17</sup> .
	Numbers in work full time Numbers in work part time	National information available annually on number of adults with learning disabilities known to social services aged 18-64 in paid work per 1,000, but no information on hours of work or pay rates (Table 9 ref 38) <sup>20</sup>
	Numbers doing voluntary work	National information available annually on number of adults

	<p>Numbers in FE full time Numbers in FE part time</p> <p>Numbers getting 5, 4, 3, 2, 1, and 0 days of activities</p>	<p>with learning disabilities known to social services aged 18-64 in voluntary work per 1,000, but no information on hours of work (Table 9 ref 38)<sup>20</sup></p> <p>DCFS collect information updated quarterly from Connexions on the number of young people (aged 16-19) with 'learning difficulties and/or disabilities' in a range of employment, education, training and other circumstances, but do not publish the information (Table 9 ref 48).</p> <p>No regularly updated national data available on the number of days of day activities used by people with learning disabilities.</p>
Health	<p>Life expectancy</p> <p>Percentage dying under 50</p> <p>Morbidity</p>	<p>No regularly updated national data available on life expectancy, percentage dying under 50 or morbidity.</p>
Income	<p>Disposable income (excluding housing benefit) excluding disability benefits</p> <p>As above but including disability benefits; all figures to be in bands (will need to exclude those in residential homes)</p>	<p>No regularly updated national data available on disposable income, either including or excluding benefits.</p>
Carers	<p>Numbers and percentage of carers getting a break</p> <p>Numbers and percentage of carers getting 1-10, 11-20, 21-30, 31-40, 41+ nights a year</p> <p>As above but for hours a week (excluding nights)</p>	<p>CSCI only report annually updated information on the number and percentage of carers of adults with learning disabilities who have received an assessment/review, and some form of information or service in past year (Table 9 ref 38)<sup>20</sup>.</p> <p>National information available annually on number of adults with learning disabilities using social services-funded home care, overnight respite and</p>

		short-term residential care, but not collated by carer or presented in terms of levels of service use (Table 9 ref 3) <sup>17</sup> .
Disability Living Allowance	Numbers and percentage on higher, middle and lower care component	DWP collect this information (updated quarterly), but currently not disaggregated in publicly available analysis tool (Table 9 ref 9) <sup>22</sup>

As the national survey of the life experiences of adults with learning difficulties<sup>10</sup> and other international large-scale data collection projects illustrate, it is perfectly possible to develop and use quantitative outcome indicators that are reliable, valid and feasible to collect – the challenge is to find ways for such indicators to retain their reliability and validity when collected on a routine basis, and to harness the political will to do so.

## Resources & Links

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Adults with Learning Difficulties in England 2003/4

<http://www.ic.nhs.uk/pubs/learndiff2004>

Community Care Statistics 2006: Referrals, Assessments and Packages of Care for Adults, England.

<http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-2006:-referrals-assessments-and-packages-of-care-for-adults-england--national-report-and-cssr-tables>

Community Care Statistics 2006: Supported Residents (Adults) England.

<http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-2006:-supported-residents-adults-england>

Department for Work and Pensions. Statistical Tabulation Tool.

<http://www.dwp.gov.uk/asd/tabtool.asp>

Government Actuary's Department

<http://www.gad.gov.uk>

Hospital Activity Statistics

[http://www.performance.doh.gov.uk/hospitalactivity/data\\_requests/index.htm](http://www.performance.doh.gov.uk/hospitalactivity/data_requests/index.htm)

Hospital Episodes Statistics.

<http://www.hesonline.nhs.uk/Ease/servlet/ContentServer?siteID=1937&categoryID=87>

Mental Health Act Commission. Count Me In: Census 2006.

<http://www.healthcarecommission.org.uk/nationalfindings/nationalthemedreports/mentalhealth/countmein/2006.cfm>

Personal Social Services Expenditure and Unit Costs England: 2005-2006.

<http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/personal-social-services-expenditure-and-unit-costs-england:-2005-06>

Personal Social Services Staff of Social Services Departments at 30 September 2006, England.

<http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/personal-social-services-staff-of-social-services-departments-at-30-september-2006-england>

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