Centre for Disability Research

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Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England

Eric Emerson & Chris Hatton

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The voice of learning disability

Learning Disability Coalition

Centre for Disability Research (CeDR), Lancaster University, UK
Email: cedr@lancaster.ac.uk

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Summary

Background

The work in this report was conducted by the Centre for Disability Research at Lancaster University on behalf of Mencap. The aim of the project was to estimate changes in the needs of adults with learning disabilities in England for social care services from 2009 to 2026. Previous estimates have suggested that the extent and pattern of need for social care services for adults with learning disabilities in England is likely to change over the next decade, changes driven by three main factors:

- Decreasing mortality among people with learning disabilities, especially in older age ranges and among children with severe and complex needs;
- The impact of changes in fertility over the past two decades in the general population;
- The ageing of the 'baby boomers', among whom there appears to be an increased incidence of learning disabilities.

It is predicted that these demographic changes will result in a significant increase in the numbers of older people with learning disabilities and young people with complex needs and learning disabilities requiring support. These increases are likely to be associated with even greater changes in demand for support due to a range of factors that will act to reduce the capacity of informal support networks to provide care, networks that have primarily relied on the unpaid labour of women. These include:

- Increases in lone parent families
- Increasing rates of maternal employment
- Increases in the percentage of older people with learning disabilities (whose parents are likely to have died or be very frail)
- Changing expectations among families regarding the person's right to an independent life.

However, the factors that are leading to increased need and demand are operating at a time of decreasing birth rates in the general population. For example, the number of children in England aged below one dropped by 15% from 660,000 in 1991 to 558,000 in 2001. Since 2001 birth rates have begun to increase, with the number of children in England aged below one rising to 620,000 in 2006. While the impact of changes in birth rates will, to an extent, be modified by reductions in child mortality, the number of children currently reaching adulthood is expected to decrease from 2008 to 2018, after which it will begin to rise.

In this report we build on methods we have developed for estimating changes in need for local areas, based on information about current users of adult social care services for people with learning disabilities and possible new entrants into adult social care services transitioning from children's services.

These methods take account of factors influencing the prevalence of learning disabilities in the context of changes in the overall population of young people in England.

The Process

The process of estimating future need involved the following six stages.

1. The number of children with Special Educational Needs (SEN) associated with learning disability in England was ascertained from the Department of Children, School and Families' (DCSF) spring 2008 School Census.
2. These data, adjusted for the effects of mortality, were used to estimate the number of children with Special Educational Needs (SEN) associated with learning disability in England who would reach 18 years of age between 2009 and 2026.
3. We derived upper, middle and lower estimates of the percentage of these children that were likely to become eligible for adult social care services under current Fair Access to Care Services (FACS) eligibility criteria.
4. We used information from the Information Centre for Health and Social Care and information extracted from the Sheffield, Merton, Sutton and Lambeth learning disability case registers to estimate the number and age profile of adults with learning disabilities who were using social care services in 2008.
5. We adjusted the population of current adult service users for the expected effects of mortality over the period 2009-2026.
6. These data were combined with estimated inflows from child services to estimate net changes in need over the period 2009-2026. For each of the three estimates of eligibility (upper, middle, lower) we investigated three approaches to the rationing of adult social care:
    a. Adult social care services would only be available to people with critical or substantial need;
    b. Adult social care services would only be available to people with critical or substantial need and 50% of people with moderate need;
    c. Adult social care services would only be available to people with critical, substantial or moderate need.

Findings: Estimated Change in Overall Need 2009-2026

All scenarios suggest sustained growth in the need for social care services for adults with learning disabilities over the period 2009-2026. Average estimated *annual* increases varied from 1.04% (lower estimate of eligibility, services only provided to new entrants with critical or substantial needs) to 7.94% (upper estimate, services are provided to new entrants with critical, substantial or moderate needs). It is notable that in our previous work, commissioned by the Department of Health, we had estimated an average annual increase of 1.10% between 2001-2011.

However, we believe that rationing access to social care to those with just critical or substantial needs is incompatible with current policy objectives for adult social care services. If these estimates are excluded the average estimated annual increases vary from 3.20% (lower estimate, services provided to 50% of new entrants with moderate needs) to 7.94%. These estimates would involve providing support to between an additional 47,000 (34%) adults (lower estimate) to 113,000 (82%) adults with learning disabilities over the next ten years.

For all estimates the annual rate of growth in need slows from 2009 to 2018/19 at which point it stabilises. However, in our estimates based on providing services to 50% of new entrants with moderate needs the annual rate of growth in need never falls below 1.9% in any given year.

The characteristics of new entrants to adult social care will depend on the assumptions used in the estimates. To give an idea of the potential range, we estimated the severity of learning disability and ethnicity of predicted new entrants to adult social care between 2009 and 2026 for the two most extreme scenarios (lower level estimate with services only provided to people with critical or substantial needs, upper level estimate with services provided to people with critical, substantial or moderate needs).

There was little difference between these two most extreme estimates with regard to the ethnic composition of predicted new entrants into social care. In both estimates over 20% of new entrants to adult social care are expected to belong to British minority ethnic communities.

There was, however, a marked difference between the two most extreme estimates with regard to the severity of intellectual disability. Increasing the estimate of the proportion of people who are likely to be eligible for adult social care services, or reducing rationing has the same effect. Both have the effect that higher level estimates (or estimates with less stringent rationing) include a significantly greater proportion of people with less severe learning disabilities. It is this group of people (people with mild or moderate learning disabilities) who are currently at greatest risk of ‘falling through the net’.

Comments

All scenarios included in our estimation procedures suggested sustained growth in the need for social care services for adults with learning disabilities over the time period 2009-2026. Our estimates that are compatible with current policy objectives for adult social care services suggests that the average estimated annual growth in need will vary from 3.20% (lower estimate, services provided to 50% of new entrants with moderate needs) to 7.94%. These estimates would involve providing support to between an additional 47,000 (34%) adults (lower estimate) to 113,000 (82%) adults with learning disabilities over the next ten years.

These estimates are based on a number of assumptions, some we believe to be highly robust, some less so. The most critical source of uncertainty in the predictions lies in estimating the likely eligibility for social care services for new entrants with mild or moderate learning disabilities. For example, people with mild learning disabilities constitute 85% of the population of young people with learning disabilities. An increase in their estimated eligibility for social care of 1% is associated with a 0.15% increase in annual average growth rates over the period 2009-2026. Most young adults with mild learning disabilities, unless they are parents, are unlikely to have ‘critical’ or ‘substantial’ needs due to their learning disability per se. However, people with mild learning disabilities do have much higher rates of mental health problems, have poorer health and are much more likely to live in poverty than their non-disabled peers. It is this combination of mild learning disabilities and additional adversity and/or health problems that is likely to determine eligibility for social care.

It is our opinion that the estimates of eligibility used in these analyses are conservative. Indeed, it is notable that the one consultation response we had that questioned our estimates did so explicitly on our (alleged) under-estimate of the eligibility for social care among young people with mild and moderate learning disabilities. However, there is a pressing need to empirically test the validity of these eligibility estimates in practice.

Background

The work in this report was conducted by the Centre for Disability Research at Lancaster University on behalf of Mencap. The aim of the project was to estimate changes in the needs of adults with learning disabilities in England for social care services from 2009 to 2026.

In 2004 we attempted to derive national estimates of future need for services for adults with learning disabilities by applying age-specific prevalence estimates to general population projections.[1 2] These estimates suggested that the extent and pattern of need for social care services for adults with learning disabilities in England is likely to change over the next decade. These changes will be driven by three main factors:[3]

- Decreasing mortality among people with learning disabilities, especially in older age ranges and among children with severe and complex needs;
- The impact of changes in fertility over the past two decades in the general population;[4]
- The ageing of the 'baby boomers', among whom there appears to be an increased incidence of learning disabilities.

These demographic changes will result in a significant increase in the numbers of older people with learning disabilities and young people with complex needs and learning disabilities requiring support. These increases are likely to be associated with even greater changes in demand for support due to a range of factors that will act to reduce the capacity of informal support networks to provide care, networks that have primarily relied on the unpaid labour of women. These factors include:

- Increases in lone parent families[5]
- Increasing rates of maternal employment[5]
- Increases in the percentage of older people with learning disabilities (whose parents are likely to have died or be very frail)[6 7]
- Changing expectations among families regarding the person's right to an independent life.

However, the factors that are leading to increased need and demand are operating at a time of decreasing birth rates in the general population. For example, the number of children in England aged below one dropped by 15% from 660,000 in 1991 to 558,000 in 2001.[8] Since 2001 birth rates have begun to increase, with the number of children in England aged below one rising to 620,000 in 2006. While the impact of changes in birth rates will, to an extent, be modified by reductions in child mortality,[8] the number of children currently reaching adulthood is expected to decrease from 2008 to 2018, after which it will begin to rise.

In this report we build on methods we have developed for estimating changes in need for local areas, based on information about current users of adult social care services for people with learning disabilities and possible new entrants into adult social care services transitioning from children's services.[9 10]

These methods take account of factors influencing the prevalence of learning disabilities in the context of changes in the overall population of young people in England.

The Process

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4. We used information from the Information Centre for Health and Social Care and information extracted from the Sheffield, Merton, Sutton and Lambeth learning disability case registers to estimate the number and age profile of adults with learning disabilities who were using social care services in 2008.
5. We adjusted the population of current adult service users for the expected effects of mortality over the period 2009-2026.
6. These data were combined with estimated inflows from child services to estimate net changes in need over the period 2009-2026.

Further details of the process are given below.

Stage 1: Identifying Children with SEN Associated with Learning Disability

Each school term the DCSF conducts a School Census, collecting data on all children attending school in England.[a] The pupil-level component of the School Census collects information on, among many other things, whether a pupil is recorded as being at the School Action Plus stage of assessment of SEN or has a Statement of SEN. If the pupil meets either of these criteria, information is collected on the primary and (for some children) secondary type of SEN. The SEN categories include four categories that are associated with learning disabilities:

- MLD – Moderate learning difficulties
- SLD – Severe learning difficulties
- PMLD – Profound and multiple learning difficulties
- ASD – Autistic spectrum disorder

The categories MLD, SLD and PMLD refer to *general* learning difficulties (i.e., what would be termed learning disabilities in non-educational settings). They do not include children with *specific* learning difficulties (e.g., dyslexia) who are identified separately in the School Census.

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[a] http://www.teachernet.gov.uk/management/ims/datacollections/sc2008/

From the spring 2008 School Census we calculated the number and percentage of children with MLD, SLD, PMLD and ASD across the 6.8 million pupils who were 4-15 years old at the commencement of the school year. We determined these *administrative prevalence rates*[b] separately for each year age group for boys and girls. We excluded children younger than 4 years of age and children older than 15 years of age as presence of SEN associated with learning disabilities is likely to be associated with early school entry and, especially for children with MLD, leaving school at age 16.

As would be expected, administrative prevalence rates of all categories of SEN (but especially MLD) rise with age across the primary school years, primarily due to delays in the identification of SEN and time-lapse between identification and the involvement of external professional staff (a criterion of being placed at School Action Plus). They then drop slightly across secondary school years. It is not possible within these data to distinguish between cohort effects (changes in the prevalence of learning disabilities across children born at different points in time) and time-related effects (changes in prevalence rates among children born in a particular year over time).

In the modelling contained in this report we made the assumption that prevalence rates of SEN associated with learning disability are *constant across different age cohorts of children*. We estimated prevalence rates from the average prevalence rate among children aged 7-15 in the spring 2008 School Census.

The estimates we used were (per 1,000 children):

- 35.8 for MLD
- 4.63 for SLD
- 1.14 for PMLD
- 8.20 for ASD

These estimates are broadly consistent with the findings of epidemiological studies of the prevalence of learning disabilities and ASD among children.[11-16] We were interested in information on the number of children with ASD as, while it is known that approximately 50% of children with ASD also have learning disabilities,[13 14] the combination of ASD and MLD/SLD/PLMD was relatively rarely recorded in the data.

To test the validity of the identification of SEN associated with learning disabilities in these data, we examined the extent to which prevalence varied by gender and social deprivation. All categories of SEN associated with learning disabilities were significantly more common among boys, with girl:boy ratios of 1:1.85 for MLD, 1:1.83 for SLD, 1:1.28 for PMLD and 1:5.73 for ASD. These associations are broadly consistent with the results of previous epidemiological studies. Social deprivation was measured by the Income Deprivation Affecting Children Index (IDACI) from the English Indices of Deprivation 2007.[17] There were significant associations between the prevalence of MLD and to a much lesser extent SLD and the area-based IDACI. There was no significant association between the prevalence of PMLD or ASD and IDACI. Again, these associations are broadly consistent with the results of previous epidemiological studies.

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[b] *Administrative* prevalence refers to the percentage of children identified through administrative records (in this case the School Census) with a particular characteristic. Administrative prevalence is influenced by the true or underlying prevalence of a particular condition and the efficiency and reliability of administrative systems in correctly identifying children with that particular characteristic.

In our estimates of the numbers of children with learning disabilities, we included children with recorded SEN of MLD, SLD or PMLD and 50% of children with recorded SEN of ASD (after taking into account the small number of children who had been identified in the data as having ASD and MLD/SLD/PLMD).

We derived estimates of the numbers of children with learning disabilities in each year age band from 0-17 by applying our prevalence estimates to current population projections of children in England.[c] This resulted in the identification of 466,000 children with learning disabilities in England aged under 18 in 2008. A breakdown of the numbers of children by category of SEN is given below in Table 1.

Table 1: Estimated Number of Children (Age Under 18) with Learning Disabilities in England 2008

SEN Category	Total Number	Average per One-Year Age Band
Moderate Learning Difficulties	394,078	21,893
Severe Learning Difficulties	50,896	2,828
Profound Multiple Learning Difficulties	12,567	698

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[c] http://www.gad.gov.uk/Demography_Data/Population/2006/england/weng06singyear.xls We used these estimates as they include all children in England including those not covered by the DCSF School Census (e.g., children being educated at home).

Stage 2: Adjusting for Child Mortality

The second stage of the process involved estimating the number of children with learning disabilities in England who would reach 18 years of age between 2011 and 2026. In order to estimate these numbers we adjusted the current cohort of children to take account of cohort attrition as a result of child mortality between the child's current age and age 18.

It has been suggested that mortality rates among people with mild learning disabilities may be similar to those of the general population.[18 19] However, given that children with mild or moderate learning disabilities (equivalent to the SEN category of MLD) are much more likely than other children to live in poverty[20] and that exposure to poverty is associated with increased child mortality,[21] we made a conservative estimate that mortality rates among children with MLD would be 50 per cent higher than those observed among children in the general population of a similar age and gender.[19] Population child mortality rates were taken from the latest data available from the Office for National Statistics.[8]

For children with SLD and children with ASD and learning disabilities we estimated mortality rates on the basis of information extracted from the Sheffield Learning Disability Case Register on child mortality over the last decade.[d] For children with PMLD we estimated annual mortality rates to be 50% higher than the rates estimated for children with SLD.[18]

The estimates we used were (per year per 1,000 children):

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

Application of these mortality estimates predicted an average of 680-690 deaths per year among the cohort of children with learning disabilities.

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[d] http://www.signpostsheffield.org.uk/health/case-register

Stage 3: Estimating the Numbers of Young People Who Are Likely to Become Users of Adult Social Care Services

Not all young people with learning disabilities will become users of social care services for adults. Two factors are particularly important when attempting to estimate the number of likely new entrants into social care services for adults.

- The percentage of potential users with learning disabilities who are likely to meet differing levels of eligibility for adult social care under the current Fair Access to Care Services (FACS) guidance.[22]
- The rationing of access to adult social care services by FACS eligibility criteria.

At present no data are available regarding the percentage of young people with varying degrees of learning disabilities who meet differing levels of eligibility for adult social care under current FACS guidance. As a result, we adopted a consultative approach to deriving estimates.

First, we asked expert organisations (e.g., member organisations of the Learning Disability Coalition, Local Government Association, Association of Directors of Adult Social Services, Information Centre for Health and Social Care, Department of Health, Office for Disability Issues, National Development Team) to provide their best estimate of the percentage of young people with MLD, SLD, PMLD, ASD and learning disabilities who, in their opinion, would meet the criteria for critical, substantial, moderate and low need.

From this response we constructed upper, middle and lower estimates of probable FACS eligibility for the four categories of SEN associated with learning disabilities. We adopted a conservative approach to this task by taking the estimate provided by this exercise as the *upper* estimate. To create the *middle* and *lower* estimates we progressively reduced the proportions of people with MLD, SLD and ASD+LD we estimated would be assessed at higher levels of eligibility to derive middle and lower estimates. We did not reduce the proportion of people with PMLD we estimated would be assessed at higher levels of eligibility as there exists a strong consensus that all people with PMLD have ‘critical’ needs. The main effect of these adjustments is to reduce the proportion of people with less severe learning disabilities in the predicted population of likely service users.

Finally, we circulated these estimates to the same set of organisations for comment. The comments received suggested that either our estimates appeared reasonable or were too conservative, especially with regard to estimating eligibility among people with less severe learning disabilities.

The estimates used in the subsequent analyses are presented below in Table 2.

Table 2: Estimates of Assessed Level of Eligible Need by SEN Associated with Learning Disabilities

Upper Estimate					
	Critical	Substantial	Moderate	Low	None
MLD	5%	10%	30%	45%	10%
SLD	30%	70%	0%	0%	0%
PMLD	100%	0%	0%	0%	0%
ASD+LD	30%	40%	20%	10%	0%
Middle Estimate					
	Critical	Substantial	Moderate	Low	None
MLD	3%	5%	25%	57%	10%
SLD	20%	70%	10%	0%	0%
PMLD	100%	0%	0%	0%	0%
ASD+LD	20%	40%	30%	10%	0%
Lower Estimate					
	Critical	Substantial	Moderate	Low	None
MLD	2%	3%	25%	45%	25%
SLD	20%	60%	10%	10%	0%
PMLD	100%	0%	0%	0%	0%
ASD+LD	15%	30%	45%	10%	0%

For each of these three estimates we investigated three approaches to the rationing of adult social care:

1. Adult social care services would only be available to people with critical or substantial need. In 2007-08, 72% of councils were operating this level of rationing.[23] However, significant concerns have been expressed regarding the conflict between this level of rationing and the importance, a policy objective strongly emphasised in *Putting People First*[24], of adopting a more *preventative* approach to social care.[23] [25] We believe that such a stringent approach to rationing is incompatible with current policy objectives and, as a result, also include two alternative scenarios.
2. Adult social care services would only be available to people with critical or substantial need and 50% of people with moderate need.
3. Adult social care services would only be available to people with critical, substantial or moderate need.

Stage 4: Estimating Attrition among Current Users of Adult Social Care Services

The most recent information available suggests that, in 2006-7, 137,000 adults with learning disabilities used adult social care services in England. [26] This estimate is lower than the estimate of 187,000 adults with learning disabilities known to health and social care services[27] as not all people known to health and social care services will be actual users of social care services in any given year. The available data does not, however, provide a detailed breakdown of the age profile of the population of current users. To do this we applied an age-profile estimated from data provided to us from the Sheffield, Merton, Sutton and Lambeth learning disabilities case registers,[e] the City of Manchester and the Metropolitan Borough of Stockport.

For this cohort of current users of adult social care services we applied year on year age-specific adjustments for predicted mortality for the period 2009-2026. The mortality estimates used were derived from actual death rates recorded by the Sheffield Case Register (1998-2007), the Sutton and Merton Case Registers (2003-2007) and the Leicestershire Case Register (1993-2005). Data from Sheffield, Merton and Sutton was provided for us by the register managers. Data from Leicestershire were extracted from a published report.[28] These mortality estimates (presented in Table 3) were derived from information covering over 60,000 person-years. For purposes of comparison, death rates (per 1,000) in the general population for 2006 were below 1 in the 20-34 year age range, below 10 in all age groups below 65, rising to 23.2 in the 65-74 age group and 64.7 in the 75-84 age group.[8] The markedly greater death rates among people with learning difficulties apparent in these figures is consistent with that reported in previous research studies.[28]

Table 3: Age-Specific Mortality Estimates

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

Stage 5: Estimating Net Changes in Adult User Population

In order to estimate net changes in the population of people with learning disabilities who use adult social care services we combined our estimates of inflows from children's services with our estimates of attrition in the cohort of current service users. Nine estimates were generated by combining the three estimates of likely eligibility (upper, medium, lower) with each of the three scenarios of rationing.

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[e] http://www.i-count.org/index.html http://www.signpostsheffield.org.uk/health/case-register

Findings: Estimated Change in Overall Need 2009-2026

Our projection for future need for social care services for adults with learning disabilities in England are presented below in Tables 4-6. Each table presents upper, middle and lower estimates of the number of eligible users under a distinct scenario of service rationing. In each table we present for each year the estimated numbers of eligible adult users of social care services and the annual percentage change from the previous year. Figures 2-4 present the data contained in Tables 4-6 in graphical form.

All scenarios suggest sustained growth in the need for social care services for adults with learning disabilities over the full time period. However, average estimated annual increases vary from 1.04% (lower estimate, services are only provided to new entrants with critical or substantial needs) to 7.94% (upper estimate, services are provided to new entrants with critical, substantial or moderate needs).

As we have stated above, we believe that rationing access to social care to those with just critical or substantial needs is incompatible with current policy objectives. If these estimates are excluded the average estimated annual increases vary from 3.20% (lower estimate, services provided to 50% of new entrants with moderate needs) to 7.94%. These estimates would involve providing support to between an additional 47,000 (34%) adults (lower estimate) to 113,000 (82%) adults with learning disabilities over the next ten years.

Table 4: Services Provided to New Entrants with Critical or Substantial Needs Only

	Estimated Eligible Users: Upper	Estimated Eligible Users: Middle	Estimated Eligible Users: Lower	% Annual Change: Upper	% Annual Change: Middle	% Annual Change: Lower
2009	142,507	140,452	139,339	4.0%	2.5%	1.7%
2010	147,757	143,707	141,514	3.7%	2.3%	1.6%
2011	152,684	146,711	143,479	3.3%	2.1%	1.4%
2012	157,443	149,578	145,325	3.1%	2.0%	1.3%
2013	161,981	152,268	147,018	2.9%	1.8%	1.2%
2014	166,367	154,817	148,579	2.7%	1.7%	1.1%
2015	170,734	157,340	150,109	2.6%	1.6%	1.0%
2016	174,851	159,660	151,464	2.4%	1.5%	0.9%
2017	178,782	161,830	152,689	2.2%	1.4%	0.8%
2018	182,484	163,821	153,763	2.1%	1.2%	0.7%
2019	185,985	165,652	154,701	1.9%	1.1%	0.6%
2020	189,472	167,464	155,617	1.9%	1.1%	0.6%
2021	193,111	169,379	156,612	1.9%	1.1%	0.6%
2022	196,936	171,421	157,702	2.0%	1.2%	0.7%
2023	200,815	173,495	158,814	2.0%	1.2%	0.7%
2024	204,810	175,642	159,979	2.0%	1.2%	0.7%
2025	209,102	178,000	161,309	2.1%	1.3%	0.8%
2026	213,371	180,333	162,614	2.0%	1.3%	0.8%
			Average	3.1%	1.8%	1.0%

Table 5: Services Provided to New Entrants with Critical or Substantial Needs and 50% of New Entrants with Moderate Needs

	Estimated Eligible Users: Upper	Estimated Eligible Users: Middle	Estimated Eligible Users: Lower	% Annual Change: Upper	% Annual Change: Middle	% Annual Change: Lower
2009	146,187	143,708	142,634	6.7%	4.9%	4.1%
2010	155,014	150,127	148,010	6.0%	4.5%	3.8%
2011	163,390	156,181	153,061	5.4%	4.0%	3.4%
2012	171,549	162,053	157,946	5.0%	3.8%	3.2%
2013	179,412	167,679	162,610	4.6%	3.5%	3.0%
2014	187,105	173,149	167,125	4.3%	3.3%	2.8%
2015	194,798	178,607	171,624	4.1%	3.2%	2.7%
2016	202,158	183,789	175,873	3.8%	2.9%	2.5%
2017	209,269	188,765	179,936	3.5%	2.7%	2.3%
2018	216,067	193,485	183,770	3.2%	2.5%	2.1%
2019	222,591	197,980	187,401	3.0%	2.3%	2.0%
2020	229,114	202,468	191,022	2.9%	2.3%	1.9%
2021	235,883	207,138	194,803	3.0%	2.3%	2.0%
2022	242,948	212,032	198,777	3.0%	2.4%	2.0%
2023	250,112	216,996	202,810	2.9%	2.3%	2.0%
2024	257,469	222,102	206,965	2.9%	2.4%	2.0%
2025	265,288	227,561	211,429	3.0%	2.5%	2.2%
2026	273,089	232,998	215,872	2.9%	2.4%	2.1%
			Average	5.5%	3.9%	3.2%

Table 6: Services Provided to New Entrants with Critical, Substantial or Moderate

	Estimated Eligible Users: Upper	Estimated Eligible Users: Middle	Estimated Eligible Users: Lower	% Annual Change: Upper	% Annual Change: Middle	% Annual Change: Lower
2009	149,867	146,965	145,929	9.4%	7.3%	6.5%
2010	162,271	156,546	154,506	8.3%	6.5%	5.9%
2011	174,097	165,651	162,643	7.3%	5.8%	5.3%
2012	185,656	174,527	170,567	6.6%	5.4%	4.9%
2013	196,842	183,090	178,202	6.0%	4.9%	4.5%
2014	207,843	191,481	185,671	5.6%	4.6%	4.2%
2015	218,862	199,875	193,140	5.3%	4.4%	4.0%
2016	229,464	207,918	200,282	4.8%	4.0%	3.7%
2017	239,757	215,699	207,182	4.5%	3.7%	3.4%
2018	249,650	223,149	213,776	4.1%	3.5%	3.2%
2019	259,197	230,309	220,101	3.8%	3.2%	3.0%
2020	268,757	237,471	226,427	3.7%	3.1%	2.9%
2021	278,655	244,898	232,994	3.7%	3.1%	2.9%
2022	288,961	252,644	239,851	3.7%	3.2%	2.9%
2023	299,408	260,498	246,806	3.6%	3.1%	2.9%
2024	310,128	268,562	253,951	3.6%	3.1%	2.9%
2025	321,473	277,121	261,548	3.7%	3.2%	3.0%
2026	332,807	285,664	269,129	3.5%	3.1%	2.9%
			Average	7.9%	6.0%	5.4%

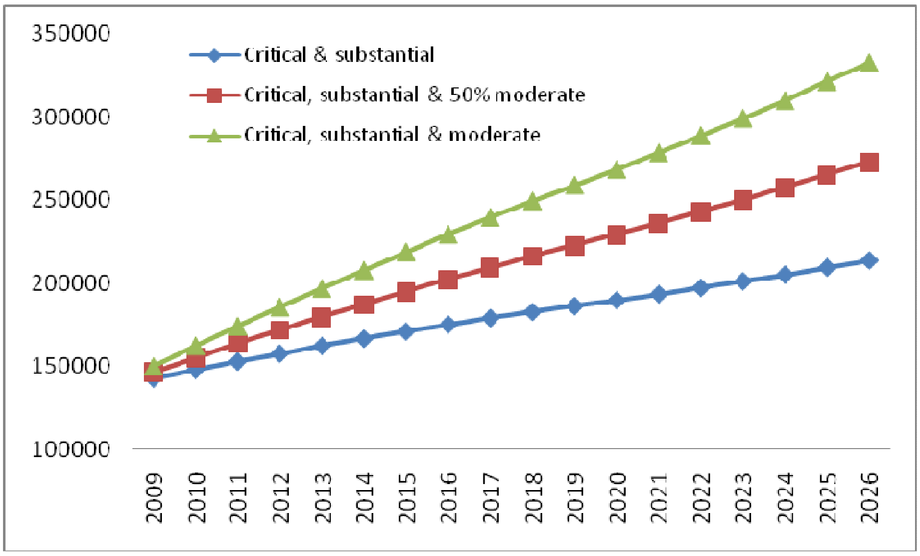

Figure 1: Predicted Need (Upper Estimate) by Level of Rationing

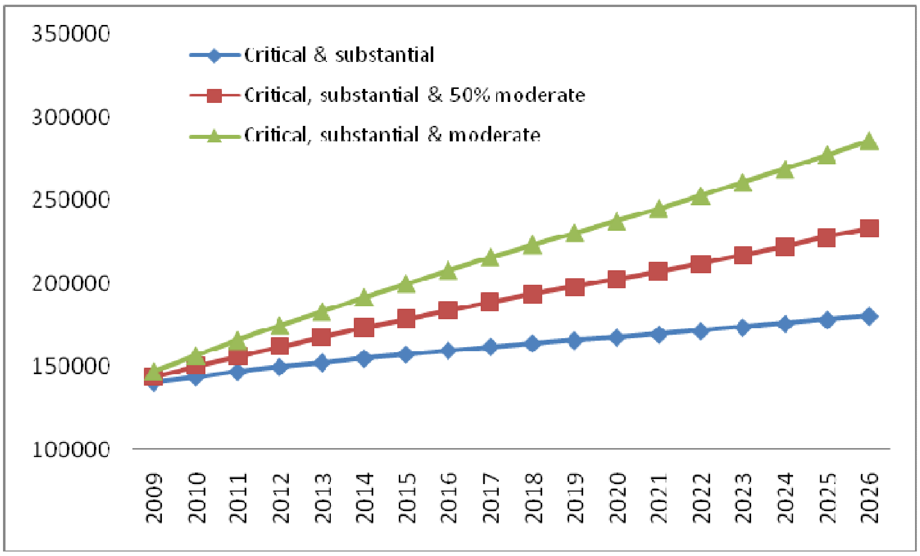

Figure 2: Predicted Need (Middle Estimate) by Level of Rationing

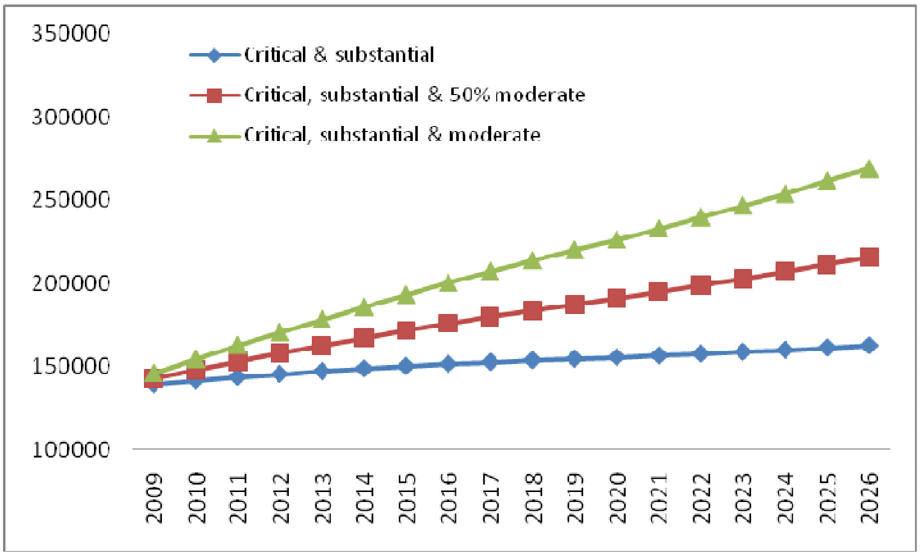

Figure 3: Predicted Need (Lower Estimate) by Level of Rationing

For all estimates the annual percentage growth rate slows from 2009 to 2018/19 at which point it stabilises. This pattern reflects changes in birth rates over the last two decades. The number of live birth in England has declined year on year from 1991 to 2001, since which time it has gradually increased. As a result, the latest population projections for England estimate that the number of children in each one year age band drops systematically from 675,000 children aged 17 years to 557,000 children aged 7 years.[f] This will mean that the total number of children reaching adulthood (and the total number of children with learning disabilities reaching adulthood) will gradually drop over the next decade, after which it will gradually begin to rise.

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[f] http://www.gad.gov.uk/Demography_Data/Population/2006/england/weng06singyear.xls

Selected Characteristics of Young People with Learning Disabilities Entering Adult Social Care Services: 2009-2026

The characteristics of new entrants to adult social care will depend on the assumptions used in the estimates. To give an idea of the potential range, a breakdown of the severity of learning disability and ethnicity (as recorded in the School Census) of predicted new entrants to adult social care between 2009 and 2026 is presented in Table 7 for the two most extreme scenarios (lower level estimate with services only provided to people with critical or substantial needs, upper level estimate with services provided to people with critical, substantial or moderate needs).

Table 7: Severity Of Learning Disability And Ethnicity Of Predicted New Entrants To Adult Social Care Between 2009 And 2026

	Lower estimate, services only provided to people with critical or substantial needs	Upper estimate, services provided to people with critical, substantial or moderate needs
Severity of Learning Disability		
Mild/Moderate	27.0%	73.6%
Severe	55.8%	21.1%
Profound Multiple	17.2%	5.2%
Ethnic Group		
African	3.2%	2.8%
Caribbean	1.7%	1.9%
Other Black Background	0.7%	0.6%
Total Black Background	*5.6%*	*5.3%*
Chinese	0.3%	0.2%
Bangladeshi	1.6%	1.4%
Indian	1.9%	1.7%
Pakistani	5.1%	4.7%
Other Asian Background	1.1%	0.8%
Total Asian Background	*10.0%*	*8.8%*
Gypsy/Romany	0.3%	0.5%
Irish	0.3%	0.3%
Traveller of Irish Heritage	0.2%	0.3%
White British	76.4%	78.0%
Other White Background	2.7%	2.5%
Total White Background	*79.9%*	*81.6%*
White and Asian	0.6%	0.6%
White and Black African	0.4%	0.4%
White and Black Caribbean	1.2%	1.3%
Other Mixed Background	1.3%	1.1%
Total ‘Mixed’ Background	*3.5%*	*3.4%*

There is little difference between these two estimates with regard to the ethnic composition of predicted new entrants into social care with nationally over 20% coming from minority ethnic communities.

There is, however, a marked difference between the two estimates with regard to the severity of intellectual disability. Increasing the estimates and reducing rationing both have the effect of increasing the proportion of predicted new entrants with less severe learning disabilities. While the proportions of people with different levels of severity of learning disabilities varies between estimates, the predicted number of people with profound multiple learning disabilities does not as all estimates assume that all people with profound multiple learning disabilities will be eligible for services. The estimated number of new entrants to adult social care services with profound multiple learning disabilities ranges between 559 and 763 per year, with an average of 630. Year by year projections are presented in Figure 5.

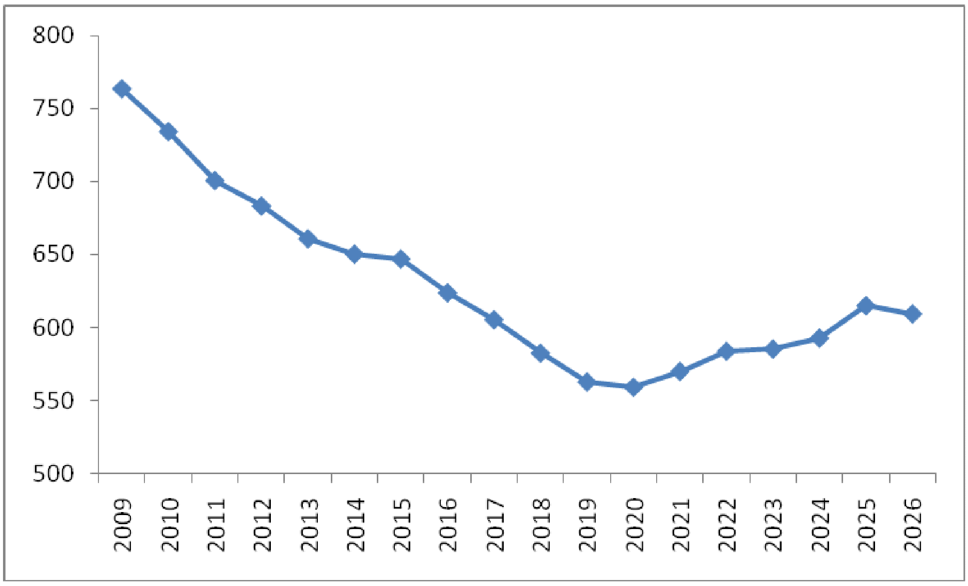

Figure 4: Predicted Number of New Entrants to Adult Social Care Services with Profound Multiple Learning Disabilities

The decrease in the number of predicted new entrants with profound multiple learning disabilities between 2009 and 2019 is the result of the reductions in the numbers of children reaching adulthood in the general population.

Summary & Comments

All scenarios included in our estimation procedures suggested sustained growth in the need for social care services for adults with learning disabilities over the time period 2009-2026. As we have stated above, we believe that rationing access to social care to those with just critical or substantial needs is in. Our estimates that are compatible with current policy objectives indicate that annual increases in need will range from 3.20% (lower estimate, services provided to 50% of new entrants with moderate needs) to 7.94%. These estimates would involve providing support to between an additional 47,000 and 113,000 adults with learning disabilities over the next ten years. In our previous work, commissioned by the Department of Health, we had estimated an average annual increase of 1.10% between 2001-2011.[27]

These estimates are based on a number of assumptions, some we believe to be highly robust, some less so. In Table 8 we list the key assumptions and data sources used and indicate the degree of confidence (from fair to very high) we feel can be placed in these assumptions/data. We also estimate the sensitivity of the predictions to any reasonably expected error in these assumptions (rated from very low to moderate).

Table 8: Assumptions and Data Included in the Projections

Assumption/Data	Confidence	Sensitivity
Age-specific general population predictions published by the Office for National Statistics	Very high	Moderate
Prevalence of learning disabilities estimated for 2008 spring School Census data	High	Low
General population age-specific child mortality estimates published by the Office for National Statistics	Very high	Very low
Adjustment of age-specific general population child mortality estimates for children with mild/moderate learning disabilities	High	Low
Child mortality estimates for children with more severe learning disabilities	Moderate	Low
Age-specific mortality estimates for adult users of learning disability services	Moderate	Low
Estimates of eligibility for new entrants with mild/moderate learning disabilities	Fair	Moderate
Estimates of eligibility for new entrants with severe learning disabilities or ASD and learning disabilities	Moderate	Low
Estimates of eligibility for new entrants with profound multiple learning disabilities	High	Very low

The most critical source of uncertainty in the predictions lies in estimating the likely eligibility for social care services for new entrants with mild or moderate learning disabilities. For example, people with mild learning disabilities constitute 85% of the population of young people with learning disabilities. An increase in their estimated eligibility for social care of 1% is associated with a 0.15% increase in annual average growth rates over the period 2009-2026. Most young adults with mild learning disabilities, unless they are parents, are unlikely to have 'critical' or 'substantial' needs due to their learning disability per se. However, people with mild learning disabilities do have much higher rates of mental health problems and are much more likely to live in poverty than their non-disabled peers.[20 29] It is this combination of mild learning disabilities and additional adversity or mental health problems that is likely to determine eligibility for social care. It is our opinion that the estimates of eligibility used in these analyses are conservative. Indeed, it is notable that the one consultation response we had that questioned our estimates did so explicitly on our (alleged) under-estimate of the eligibility for social care among young people with mild or moderate learning disabilities. Clearly, there would be considerable value in empirically testing these eligibility estimates.

There are a number of factors that would have an impact on future need that we did not take into account. These included:

- Effects due to international migration. We believe that *at a national level* any net effects are likely to be minimal. Effects may be of local importance, however, in areas with high concentrations of refugee children.
- Changes in the incidence of learning disabilities over time. We do not feel that there are sufficient grounds for building in estimates of changes in the incidence of learning disabilities. Factors that are likely to lead to an increase in the incidence of learning disabilities include increases in maternal age (associated with higher risk factors for some conditions associated with learning disabilities, such as Down's syndrome), improved survival of 'at risk' infants (e.g., very low birth weight or very pre-term infants), increasing levels of HIV and AIDS in children. Factors that are likely to lead to a decrease in incidence include the increasing availability of prenatal screening for Down's syndrome, improving health care and support resulting in fewer 'at risk' infants developing learning disabilities, reductions in child poverty rates and improvements in early years services. The net effect of these competing pressures on the incidence of learning disabilities is not known. We consider it unlikely, however, that any changes that do occur will be of a magnitude to have a significant impact on these predictions.
- Changes in mortality rates among people with learning disabilities over time. Current trends suggest that mortality rates among people with learning disabilities should continue to fall (as they are expected to do in the general population). It is not possible, however, top predict these changes with any degree of precision. Given that the model used is relatively insensitive to changes in mortality rates (i.e., such changes have little impact on the final estimate), we decided to make a conservative assumption that mortality rates would remain constant. Any error here would lead us to marginally underestimating future need.

Finally, it must be stressed that our predictions are based on estimates of ‘need’ rather than ‘demand’. Changes in demand are likely to outstrip changes in need due to a variety of factors combining to reduce the capacity of informal support networks to provide care, networks that have primarily relied on the unpaid labour of women. As noted above, these factors include:

- Increases in lone parent families[5]
- Increasing rates of maternal employment[5]
- Increases in the percentage of older people with learning disabilities (whose parents are likely to have died or be very frail)[6 7]
- Changing expectations among families regarding the person’s right to an independent life.

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