



Centre for Disability Research

Estimating Future Numbers of Adults with Profound Multiple Learning Disabilities in England

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Summary

Background

The work in this report was conducted by the Centre for Disability Research (CeDR) at Lancaster University on behalf of the Department of Health. The aim of the project was to estimate change in the future numbers of adults with profound multiple learning disabilities (PMLD) in England over the period 2009 to 2026. The report builds on previous work undertaken by CeDR on estimating future need for social care services for adults with learning disabilities in England.¹

Change in the future numbers of adults with PMLD in England would result from change in one of four key factors:

- Change in birth rates in the general population;
- Change in the incidence of children being born with or acquiring PMLD;
- Change in infant and child mortality among children being born with PMLD;
- Change in mortality among adults with PMLD;

The Process

The process of estimating the future numbers of adults with PMLD involved the following five stages.

1. The number of children with Special Educational Needs (SEN) associated with PMLD 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 and projected future changes in prevalence, were used to estimate the number of children with PMLD in England who would reach 18 years of age between 2009 and 2026.
3. We used information from the Sheffield learning disability case register to estimate the number and age profile of adults with PMLD in England in 2008.
4. We adjusted the population of adults with PMLD for the expected effects of mortality over the period 2009-2026.
5. These data were combined with estimated inflows from child services to estimate net changes over the period 2009-2026.

Findings: Estimated Change 2009-2026

The data and assumptions used in these analysis suggested sustained and accelerating growth in the numbers of adults with PMLD in England over the time period 2009-2026 (and hence the need and demand for health and social care services for adults with PMLD), with an average annual percent increase of 1.8%. The rate of increase grows markedly toward the latter end of the forecast period due to increases in birth rates in the general population.

The estimated number of people with PMLD who will become adults (i.e., reach age 18) over the forecast period is relatively constant over the coming decade due to a decline in the number of children reaching adulthood in the general population. Thus, while the prevalence of PMLD appears to be increasing, the actual number of new adults remains relatively static as it is counterbalanced by wider demographic changes.

In an 'average' area in England with a population of 250,000 these analyses suggest:

- The number of adults with people with PMLD receiving health and social care services will rise from 78 in 2009 to 105 in 2026
- The number of young people with PMLD becoming adults in any given year will rise from 3 in 2009 to 5 in 2026

These rates will be higher in communities that: (1) have a younger demographic profile; or (2) contain a greater proportion of citizens from Pakistani and Bangladeshi communities. These projected rates will not be influenced by level of socio-economic deprivation.

Overall, it is estimated that 29% of new adults with PMLD will belong to a British minority ethnic community.

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 mortality rates. However, the overall pattern of predictions remains consistent even if these are varied substantially.

Background

The work in this report was conducted by the Centre for Disability Research (CeDR) at Lancaster University on behalf of the Department of Health. The aim of the project was to estimate change in the future numbers of adults with profound multiple learning disabilities (PMLD) in England over the period 2009 to 2026.

The report builds on previous work undertaken by CeDR on estimating future need for social care services for adults with learning disabilities in England.¹ This recent report suggested sustained growth in the need for social care services for adults with learning disabilities over the period 2009-2026. If it is assumed that rationing access to social care to those with just critical or substantial needs is incompatible with current policy objectives, the average estimated annual increase in need varies from 3.2% to 8.0%. Furthermore, we estimated that over 20% of new entrants to adult social care will belong to British minority ethnic communities. This report was, however, about *all* people with learning disabilities.

In the present report we focus specifically on predicting future change in the numbers of adults with profound and multiple learning disabilities, all of whom are likely to become users of health and social care services.

The Process

The process of estimating the future numbers of adults with PMLD involved the following five stages.

1. The number of children with Special Educational Needs (SEN) associated with PMLD 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 and projected future changes in prevalence, were used to estimate the number of children with PMLD in England who would reach 18 years of age between 2009 and 2026.
3. We used information from the Information Centre for Health and Social Care and information extracted from the Sheffield learning disability case register to estimate the number and age profile of adults with PMLD in England in 2008.
4. We adjusted the population of adults with PMLD for the expected effects of mortality over the period 2009-2026.
5. These data were combined with estimated inflows from child services to estimate net changes over the period 2009-2026.

Further details of the process are given below.

Stage 1: Identifying Children with SEN Associated with Profound Multiple 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 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 the category of PMLD – profound and multiple learning difficulties.

DCSF define PMLD in the following terms:

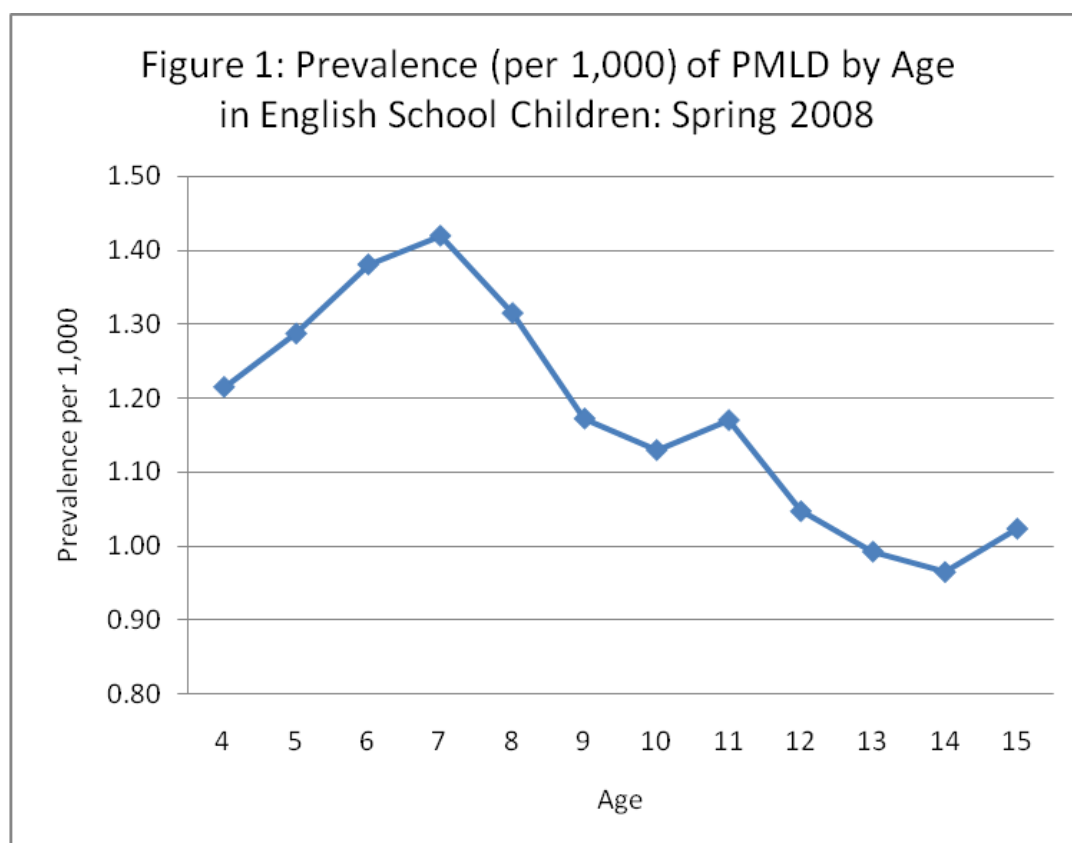
Children with profound and multiple learning difficulties have complex learning needs. In addition to very severe learning difficulties, the children will have other significant difficulties, such as physical disabilities, sensory impairment or a severe medical condition. They require a high level of adult support, for their personal care as well as for their learning needs. They are likely to need sensory stimulation and a curriculum that is broken down into very small steps. Some children with profound and multiple learning difficulties communicate by gesture, eye pointing or symbols; others communicate by using very simple language.^b

^a <http://www.teachernet.gov.uk/management/ims/datacollections/sc2008/>

^b <http://www.everychildmatters.gov.uk/deliveringservices/multiagencyworking/glossary/?asset=glossary&id=22777>

From the spring 2008 School Census we calculated the number and percentage of children with PMLD from the 6.8 million pupils who were recorded as being 4-15 years old at the commencement of the school year. We determined these *administrative prevalence rates*^c 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, possibly, leaving school at age 16.

The prevalence rates of PMLD by age are shown in Figure 1.



As can be seen, the prevalence of PMLD shows a marked decrease from 7 to 15 years of age. These changes are equivalent to an annual 4.8% increase in the prevalence of PMLD.

It is not possible within these data to know whether this reflects a cohort effect (changes in the prevalence of learning disabilities across children born at different points in time) or time-related effects (changes in prevalence rates among children born in a particular year over time, possibly due to mortality).

For three reasons, it appears likely that these reflect cohort effects (i.e., an increase in the incidence and prevalence of people with profound and multiple learning disabilities among children born more recently).

^c *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.

- First, it appears unlikely that the observed decline in prevalence between 7 to 15 years of age can simply be attributed to the effects of mortality. To do so would require mortality rates of approximately 40 per 1,000, four times greater than previously reported rates (see below).
- Second, it is considered highly unlikely that children with people with profound and multiple learning disabilities will become 'lost to the system'.
- Finally, recent research based on the Sheffield Case Register has reported marked increases in the *numbers* of people with PMLD between 2003 and 2008 in the young adult age range.² Re-analysis of these data controlling for changes in the numbers of children in the general population in Sheffield at these points in time indicates that the changes reported in Sheffield are equivalent to an annual increase in the prevalence of PMLD of 4.7%.

Given the close similarity of these estimates (4.8%, 4.7%) from two very different sources, it appears reasonable to conclude that the prevalence of PMLD in the older child/young adult age range is increasing by up to 4-5% on a year by year basis.

The decrease in prevalence rates below the age of 7 may reflect a real decrease in the prevalence of PMLD. However, given that all categories of SEN show similar decreases in administrative prevalence in these age groups, it is more likely that this drop in administrative prevalence reflects a delay in identification of SEN at School Action Plus stage of assessment of SEN.

To test the validity of the identification of SEN associated with PMLD in these data, we examined the extent to which prevalence varied by gender, ethnicity and social deprivation.

- PMLD was significantly more common among boys, with a girl:boy ratio of 1:1.28.
- When controlling for the effects of age and ethnicity, there was no significant association between the prevalence of PMLD and social deprivation (as measured by the Income Deprivation Affecting Children Index (IDACI) from the English Indices of Deprivation 2007).³
- When controlling for the effects of age and social deprivation, there were significant associations between the prevalence of PMLD and ethnic group, with particularly high rates of PMLD among Pakistani families.

All of these associations are broadly consistent with the results of previous research.⁴⁻⁶

We derived estimates of the numbers of children with PMLD in England in each year age band from 0-17 by applying our age-specific prevalence estimates to current population projections of children in England.^d

- For children below the age of 7 we assumed that the prevalence of PMLD would continue to increase by 4.8% in each successive year group.
- For children above the age of 15 we assumed that the prevalence of PMLD would decrease by 4.8% in each successive year group.

^d 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).

This resulted in the identification of 14,744 children with PMLD in England aged under 18 in 2008. A breakdown of the numbers of children by age is given below in Table 1.

Table 1: Estimated Number of Children (Age Under 18) with PMLD in England 2008		
Age	Estimated Prevalence Rate (per 1,000 children)	Estimated Number of Children
0	1.97	1,285
1	1.88	1,223
2	1.79	1,113
3	1.71	1,037
4	1.63	976
5	1.56	899
6	1.49	832
7	1.42	791
8	1.31	749
9	1.17	687
10	1.13	674
11	1.17	716
12	1.05	637
13	0.99	607
14	0.96	603
15	1.02	649
16	0.97	640
17	0.93	626
Total		14,744

Stage 2: Adjusting for the Effects of Child Mortality

The second stage of the process involved estimating the number of children with PMLD in England who would reach 18 years of age between 2009 and 2026. In order to estimate these numbers we adjusted the current estimated numbers of children to take account of the risks of child mortality between the child's current age and age 18.

For children with PMLD we estimated annual mortality rates to be 50% higher than the rates estimated for children with SLD extracted from the Sheffield Learning Disability Case Register on child mortality over the last decade.^e Such an estimate is consistent with the results of previous epidemiological research.⁷ The starting estimate we used for 2009 was 11.1 deaths per year per 1,000 children with PMLD. However, given that child mortality rates in England has shown a persistent decline over the past two decades (by approximately 2% per annum), we assumed that these proportional declines in mortality would continue over the next two decades and also apply to children with PMLD. As a result we reduced the estimated mortality rates from the base of 11.1 deaths per year per 1,000 children by 2% each year (reaching 7.1 deaths per year per 1,000 children by 2026).

^e <http://www.signpostsheffield.org.uk/health/case-register>

Stage 3: Estimating the Number of Adults with PMLD in England

No information is collected nationally on the number of adults with PMLD in England. As a result it is necessary to make estimates from other sources. To do this we assumed:

1. That the prevalence of PMLD at age 18 would be 4.8% lower than the prevalence of PMLD estimated for children age 17. (This, in effect, sets the base number of adults with PMLD at a specific age from which the rest of the population can be estimated.)
2. That the age profile of the population of adults with PMLD would mirror that reported for Sheffield.²

For this cohort of adults with PMLD 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.⁸

Given that these estimates are for all users of services for people with learning disabilities (primarily people with severe learning disabilities), we assumed that mortality rates among adults with PMLD would be 50% greater than for all users of services for people with learning disabilities. We also assumed, as above, that proportional reductions in mortality rates observed in the general population over the past two decades would continue over the next two decades and also apply to adults with PMLD. The mortality estimates we used are presented in Table 2.

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.⁹

Age Group	20-29	30-39	40-49	50-59	60-69	70-79	80+
Estimated annual mortality rate (per 1,000) 2009	7.60	9.93	12.91	32.07	52.44	105.06	177.88
Estimated annual decrease in mortality rate	0.75%	0.50%	1.10%	1.85%	2.10%	1.80%	1.00%

Stage 5: Estimating Net Changes in the Numbers of Adults with PMLD in England

In order to estimate net changes in the population of people with PMLD in England we combined our estimates of inflows from childhood with our estimates of attrition in the cohort of current adults with PMLD.

Findings: Estimated Change in the Number of Adults with PMLD in England 2009-2026

The estimated number of adults with PMLD in England is presented in Table 3 and represented graphically in Figure 2.

	Total Adult	% Change (Annual)	% Change (from 2008)
2008	16,036		
2009	16,234	1.23%	1.23%
2010	16,442	1.28%	2.53%
2011	16,665	1.36%	3.92%
2012	16,897	1.39%	5.37%
2013	17,083	1.10%	6.53%
2014	17,272	1.11%	7.70%
2015	17,488	1.25%	9.06%
2016	17,777	1.65%	10.85%
2017	18,024	1.39%	12.39%
2018	18,276	1.40%	13.96%
2019	18,583	1.68%	15.88%
2020	18,925	1.84%	18.01%
2021	19,299	1.98%	20.35%
2022	19,728	2.22%	23.02%
2023	20,218	2.49%	26.08%
2024	20,755	2.66%	29.43%
2025	21,351	2.87%	33.15%
2026	22,035	3.20%	37.41%

As can be seen, these estimates suggest a sustained and accelerating growth in the number of adults with PMLD in England over the period, with an average annual percent increase of 1.8%. The rate of increase grows markedly toward the latter end of the forecast period due to increases in birth rates in the general population.

In an 'average' area in England with a population of 250,000 these analyses suggest:

- The number of adults with people with PMLD receiving health and social care services will rise from 78 in 2009 to 105 in 2026
- The number of young people with PMLD becoming adults in any given year will rise from 3 in 2009 to 5 in 2026

These rates will be higher in communities that: (1) have a younger demographic profile; or (2) contain a greater proportion of citizens from Pakistani and Bangladeshi communities. These projected rates will not be influenced by level of socio-economic deprivation.

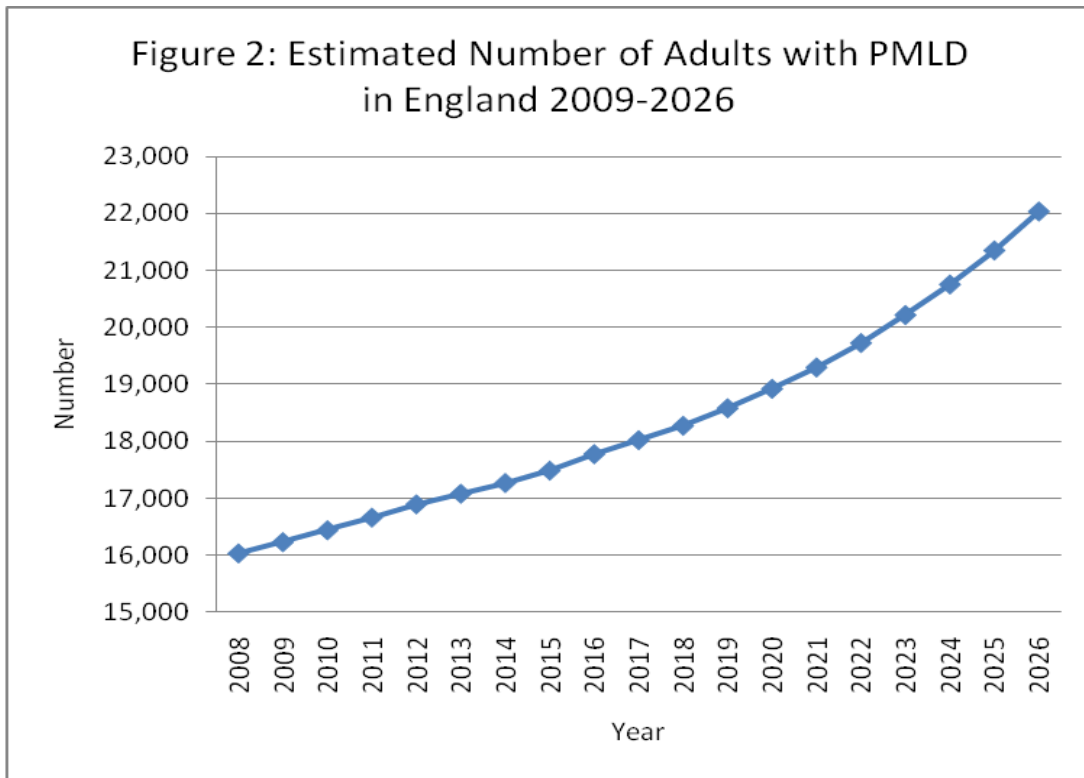
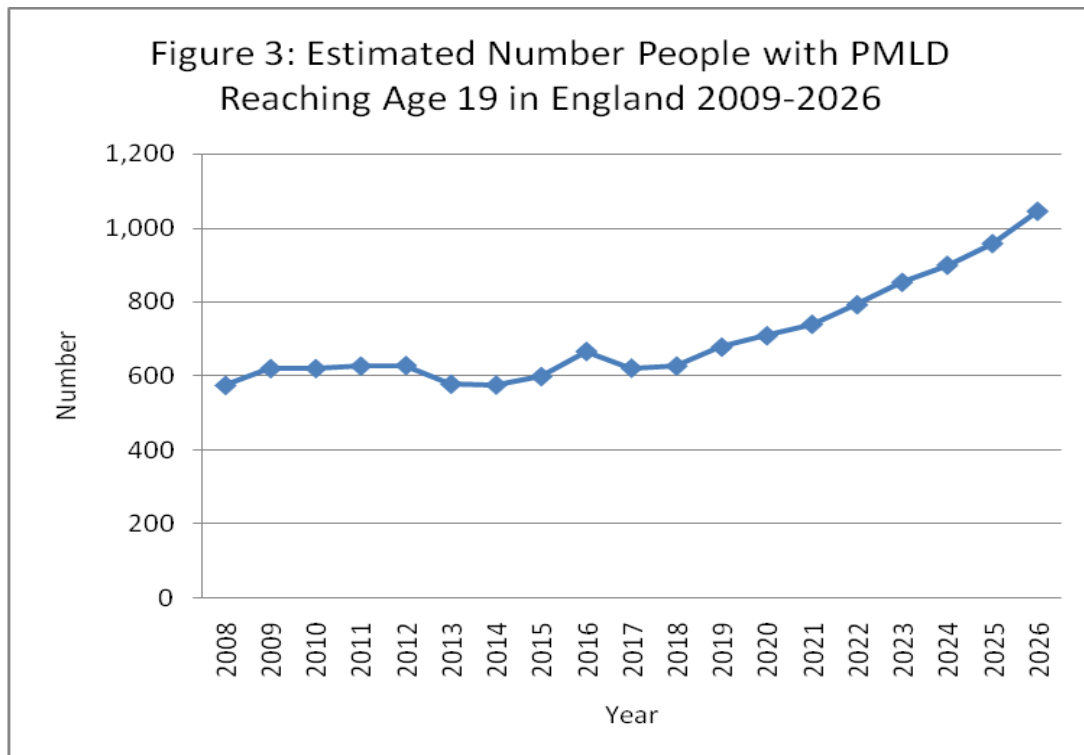


Figure 3 shows the estimated number of people with PMLD who will become adults (i.e., reach age 18) over the forecast period. This number is relatively constant over the coming decade due to a decline in the number of children reaching adulthood in the general population. Thus, while the prevalence of PMLD appears to be increasing, the actual number of new adults remains static as it is counterbalanced by wider demographic changes.



The ethnic composition of children, and hence future adults, with PMLD in England is given in Table 4. As can be seen, it is estimated that 29% of new adults with PMLD will belong to a British minority ethnic community (as defined in the School Census).

White British	71.2%
Pakistani	7.9%
African	3.4%
Any Other White Background	3.3%
Indian	2.2%
Bangladeshi	2.1%
Any Other Ethnic Group	1.6%
Any Other Mixed Background	1.5%
Any Other Asian Background	1.4%
Caribbean	1.4%
White and Black Caribbean	1.0%
Any Other Black Background	0.8%
White and Asian	0.8%
Irish	0.4%
White and Black African	0.4%
Chinese	0.3%
Gypsy/Romany	0.2%
Traveller of Irish Heritage	0.1%

The most critical source of uncertainty in the predictions lies in estimating mortality rates. However, the overall pattern of predictions remains consistent if these are varied. For example,

- Assuming that age-specific mortality rates for adults with PMLD are twice as high (rather than 1.5 times as high) as for adults users of learning disabilities services only reduces the average annual growth rate from 1.78% to 1.44%.
- Assuming that mortality rates for children with PMLD are twice as high as estimated (22.1 rather than 11.1 per 1,000 per year) only reduces the average annual growth rate from 1.78% to 1.49%.
- Assuming both these differences to be true only reduces the average annual growth rate from 1.78% to 1.13%.

Summary & Comments

The data and assumptions used in these analysis suggested sustained and accelerating growth in the numbers of adults with PMLD in England over the time period 2009-2026 (and hence the need and demand for health and social care services for adults with PMLD).

These estimates are based on a number of assumptions, some we believe to be highly robust, some less so. In Table 5 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.

Assumption/Data	Confidence
Age-specific general population predictions published by the Office for National Statistics	Very high
Prevalence of PMLD estimated for 2008 spring School Census data	High
General population age-specific child mortality estimates published by the Office for National Statistics	Very high
Adjustment of age-specific general population child mortality estimates for children with PMLD	Moderate
Age-specific mortality estimates for adults with PMLD	Moderate

References

1. Emerson E, Hatton C. Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England Lancaster: Centre for Disability Research, Lancaster University, 2008.
2. Parrott R, Wolstenholme J, Tilley N. Changes in demography and demand for services from people with complex needs and profound multiple learning disabilities. *Tizard Learning Disability Review* 2008;13(3):26-34.
3. Noble M, McLennan D, Wilkinson K, Whitworth A, Barnes H, Dibben C. The English Indices of Deprivation 2007. London: Communities and Local Government, 2008.
4. Einfeld S, Emerson E. Intellectual disability. In: Rutter M, Bishop D, Pine D, Scott S, Stevenson J, Taylor E, et al., editors. *Rutter's Child and Adolescent Psychiatry*. 5th ed. Oxford: Blackwell, 2008.
5. Leonard H, Wen X. The epidemiology of mental retardation: challenges and opportunities in the new millennium. *Mental Retardation and Developmental Disabilities Research Reviews* 2002;8:117-134.
6. Roeleveld N, Zielhuis GA, Gabreels F. The prevalence of mental retardation: a critical review of recent literature. *Developmental Medicine & Child Neurology* 1997;39:125-132.
7. Patja K, Mölsä P, Iivanainen M. Cause-specific mortality of people with intellectual disability in a population-based, 35-year follow-up study. *Journal of Intellectual Disability Research* 2001;45(1):30-40.
8. Tyrer F, Smith LK, McGrother CW. Mortality in adults with moderate to profound intellectual disability: a population-based study. *Journal of Intellectual Disability Research* 2007;51(7):520-527.
9. Office for National Statistics. Population Trends 132. London: Office for National Statistics, 2008.