Estimating the Need for Social Care Services for Adults with Disabilities in England 2012-2030

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Contents

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Summary

The aim of the project was to estimate changes in the need for social care services for adults with disabilities in England between 2012 and 2030. The project built upon and extended our previous work on estimating future need for social care services among adults with learning disabilities. The latest update of our previous work suggested that there will be sustained growth in the need for social care services for adults with learning disabilities over the time period 2011-2030, with estimated average annual increases varying from 1.2% to 5.1% (average 3.2%).

Our previous approach was, however, based on a number of assumptions, some of which we believe to be highly robust, some less so. The most critical source of uncertainty in the model was in the validity of our estimates of the likely eligibility for social care services for new entrants at different levels of 'need', especially for potential new entrants with less severe disabilities. In our previous work we used estimates developed through a process of consultation with relevant stakeholders (primarily disabled people's organisations and field agencies). One of the key aims of the present project was to test out and refine these assumptions through field-based research. Other aims of the present project were to:

- update the estimates based on revised information;
- extend the model to other adults with disabilities.

Our proposed primary research involved attempting to collect information on the assessed level of eligibility for samples of 50 children aged 14-16 identified as having SEN in 10 CASSRs. In order to compensate for potential drop out we initially recruited 18 CASSRs who all indicated a strong commitment to participating in the project. Unfortunately, the fieldwork took place during 2010/11, a period of unprecedented turmoil within CASSRs in England. Despite extending the period of data collection by several months, only six CASSRs were able to provide any data and only two CASSRs were able to provide data on the target sample of 50 children. As a result, we were only able to collect information on 223 young people (45% of the target sample).

Given the difficulties we encountered in our field work, we agreed with NIHR SSCR that we would also undertake some exploratory analyses of the association between SEN and the experimental disability statistics collected by DfE in Spring 2011. The aim of these analyses was to explore the relationship between SEN and disability (as defined under the Equality Act 2010) and to determine whether this information could be used to strengthen the estimates of assessed level of need for adult social care services. Unfortunately, the results of these analyses suggested that the disability data collected by the DfE were subject to a number of serious biases associated with social exclusion and socio-economic position that made their use untenable in the present project.

We were, however, able to use the new field-generated estimates of eligibility to: (1) update our previous work on estimating future need for adult social care services for people with learning disabilities; and (2) extend this work to estimating future need for adult social care services for people with physical disabilities (including sensory impairment) in the age range

19-30. To estimate future need beyond this age point would require making important assumptions about the annual age-specific incidence (onset) of serious physical and sensory impairments in adults. There is, at present, insufficient information to make these assumptions with any degree of confidence. However, such information will become available in the near future with the release of Wave 2 data from the Office for Disability Issues' longitudinal *Life Opportunities Survey*.[1]

All of the scenarios included in our estimation procedures suggested sustained growth in the need for social care services for adults with physical or learning disabilities over the time period 2012-2030.

- For younger adults with physical disabilities compound annual growth rates vary from 1.8% to 6.5%. A 'no growth' scenario in the number of users of adult social care services for young adults with physical disabilities could only be achieved by either cutting services to existing users or by rationing access to services to young adults with physical disabilities with 'critical' need and 61% of those with 'substantial' need.
- For adults with learning disabilities compound annual growth rates vary from 2.0% to 2.7%. A 'no growth' scenario in the number of users of adult social care services for adults with learning disabilities could only be achieved by either cutting services to existing users or by rationing access to services to young people with learning disabilities with 'critical' need and just 25% of those with substantial need.

As we have argued above, rationing social care to people with critical or substantial needs is inconsistent with the policy objective strongly emphasised in *Putting People First*[2] of adopting a more *preventative* approach to social care.[3-5]

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

- Effects due to international migration;
- Changes in the incidence of disability over time;
- Changes in mortality rates among people with disabilities over time.

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. These factors include:

- Increases in lone parent families[6]
- Increasing rates of maternal employment[6]
- Increases in the percentage of older people with learning disabilities (whose parents are likely to have died or be very frail)[7 8]
- Changing expectations among families regarding the person's right to an independent life.

Background

The work in this report was conducted by the Centre for Disability Research at Lancaster University. The aim of the project was to estimate changes in the need for social care services for adults with disabilities in England between 2012 and 2030. The project builds upon and extends our previous work on estimating future need for social care services among adults with learning disabilities.[9-13]

In 2004 we were funded by the Department of Health to derive national estimates of future need for services for adults with learning disabilities. We did this by applying age-specific prevalence estimates to general population projections.[10 11] These estimates suggested that the extent and pattern of need for social care services for adults with learning disabilities in England would 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;[14-17]
- The impact of changes in fertility over the past two decades 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.[18] Since 2001 birth rates have begun to increase, with the number of children in England aged below one being predicted to rise to 720,000 in 2014 before falling again to 680,000 by 2027.[19] While the impact of changes in birth rates will, to an extent, be modified by reductions in child mortality,[18] the number of children currently reaching adulthood is expected to decrease from 645,000 in 2012 to 577,000 in 2019, after which it will begin to rise reaching a peak of 740,000 in 2032;[19]
- The ageing of the 'baby boomers', among which there is an increased incidence of learning disabilities.[20 21]

We estimated that these demographic changes would 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. We also suggested that these increases were 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 included:

- 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.

Following this initial exercise we received funding from the Department of Health, Mencap and the Learning Disability Coalition to develop an alternative method of estimating future need. [9 12 13] This method used information from the Department for Education's National Pupil Database on the number of children with Special Educational Need associated with learning disabilities, information from the NHS Information Centre on Health and Social Care on the number of current users of adult

social care services with learning disabilities, and disability and age-specific mortality data to project national changes in the need for adult social care support for people with learning disabilities. These projections were cited in the 2009 Green Paper *Shaping the Future of Care Together,* the 2009 White Paper update *Valuing People Now: A new three-year strategy for people with learning disabilities* and the final report of the *Dilnot Commission on Funding of Care and Support*.[22-24]

The latest update of this work suggested that there will be sustained growth in the need for social care services for adults with learning disabilities over the time period 2011-2030, with estimated average annual increases varying from 1.2% to 5.1% (average 3.2%).[13] These estimates were marginally lower than, but not as varied as, those we produced in 2008.[9] We also estimated that:

- approximately 25% of new entrants to adult social care with learning disabilities will belong to minority ethnic communities;
- approximately one in three of new entrants will come from a home in which the child is eligible for Free School Meals (nationally one in six children in this age range are eligible for Free School Meals);
- by 2030 the number of adults aged 70+ using social care services for people with learning disabilities will more than double.

The major benefits of this revised approach to estimating future need is that they make use of the best available information on the number of children with learning disabilities who are approaching adulthood and the best available information on the existing population of users of adult social care services.

The method is, however, based on a number of assumptions, some of which we believe to be highly robust, some less so.[13] The most critical source of uncertainty in the model is the validity of our estimates of the likely eligibility for social care services for new entrants at different levels of 'need'.[25 26] This is especially true of new entrants with less severe disabilities. In our previous work we used estimates developed through a process of consultation with relevant stakeholders (primarily disabled people's organisations and field agencies). One of the key aims of the present project was to test out and refine these assumptions through field-based research. Other aims of the present project were to:

- update the estimates based on revised information;
- extend the model to other adults with disabilities.

Refining Estimates of Eligibility for Adult Social Care

The model we had developed included assumptions about the probability that a young adult with a specific Special Educational Need (SEN) would have no, low, moderate, substantial or critical needs for adult social care services.[15 16]

Field-Based Estimates

We proposed undertaking primary research in a sample of 10 Councils with Adult Social Services Responsibilities (CASSRs). In each CASSR we proposed to ascertain for a random sample of 50 children aged 14-16 identified as having SEN in the School Census whether each young person would have no, low, moderate, substantial or critical needs for adult social care services on transition to adult services. We proposed to cap the sample size for each category of primary SEN at 50 and otherwise sample proportionally by prevalence of primary SEN classification.

In order to compensate for potential drop out we initially recruited 18 CASSRs who all indicated a strong commitment to participating in the project. Unfortunately, the fieldwork took place during 2010/11, a period of unprecedented turmoil within CASSRs in England. Despite extending the period of data collection by several months, only six CASSRs were able to provide any data and only two CASSRs were able to provide data on the target sample of 50 children. As a result, rather than collecting information on 500 young people with SEN across 10 CASSRs, we were only able to collect information on 223 young people (45% of the target sample) aged 15-17 (74% boys, 26% girls).

Table 1 shows the percentage of children who CASSR staff judged would be eligible for adult social care at differing levels of need separately for types of primary SEN. Only categories of SEN for which we had information on 10 or more children are reported.

Table 1: Estimates of Assessed Level of Eligible Need by SEN

	n	Critical	Substantial	Moderate	Low	None
Moderate Learning Difficulty	41	0%	15%	7%	7%	71%
Severe Learning Difficulty	19	26%	42%	0%	5%	26%
Profound Multiple Learning Difficulty	11	27%	73%	0%	0%	0%
Autism Spectrum Disorder	48	4%	31%	15%	4%	46%
Behaviour Emotional and Social Difficulties	33	0%	21%	0%	0%	79%
Speech Language and Communication Needs	33	0%	30%	6%	6%	58%
Physical Disability	19	5%	37%	5%	5%	47%
Hearing Impairment	10	0%	0%	10%	20%	70%
Total	223	5%	27%	6%	5%	57%

Figure 1 compares the estimates of assessed level of need derived from the field work with the estimates we had previously used (based on stakeholder consultation). As can be seen, the results of the two processes give broadly similar results. The only statistically significant differences are the

lower rates of assessed level of need based on fieldwork estimates for Severe Learning Difficulty (SLD) (Critical and Substantial) and Profound Multiple Learning Difficulty (PMLD) (Critical).

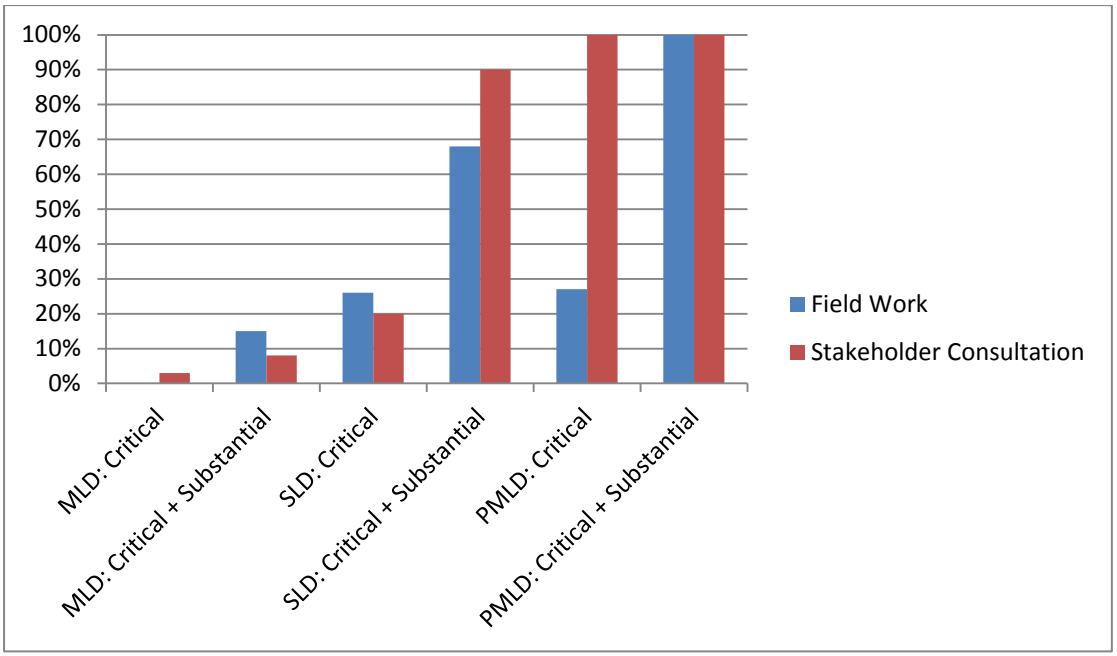

Figure 1: Estimates of assessed level of need derived from field work and based on previous stakeholder consultation

There were no statistically significant gender differences in assessed level of need within any SEN category.

DfE SEN and Disability Data

Given the difficulties we encountered in our planned field work, we agreed with NIHR SSCR that we would also undertake some exploratory analyses of the association between SEN and the experimental disability statistics collected by DfE in Spring 2011. The aim of these analyses was to explore the relationship between SEN and disability (as defined under the Equality Act 2010) and to determine whether this information could be used to strengthen the estimates of assessed level of need for adult social care services. Unfortunately, the results of these analyses, which are presented in detail in Appendix 1, suggested that the disability data collected by the DfE were subject to a number of serious biases associated with social exclusion and socio-economic position that made their use untenable in the present project.

The Process

Our process of estimating future need for social care for a given group of disabled adults involves the following six stages:

1 Ascertaining the number of children in England with SEN associated with the adult disability category in question from the latest available DfE School Census.
2 Adjusting these data for the effects of child mortality to estimate the number of children with SEN associated with the adult disability category in question who would reach 18 years of age between 2012 and 2030.
3 Appling estimates of the percentage of these children that are likely to become eligible for adult social care services under differing eligibility criteria.
4 Using information from the NHS Information Centre for Health and Social Care to estimate the number and age profile of disabled adults using social care services in 2011/12.
5 Adjusting the population of current adult service users for the expected effects of mortality over the period 2012-2030.
6 Combining these estimates with estimated inflows from child services to estimate net changes in need over the period 2012-2030.

This procedure is dependent on the availability of particular sources of information. These include two critical pieces of information:

- Information on the number of adults with a particular disability that are currently using adult social care services;
- The existence of a category (or categories) of SEN that can plausibly be used as proxy measures for the presence of impairments associated with categories of adult disability.

Information on current users of adult social care is collected from CASSRs by the NHS Information Centre for Health and Social Care.[a] Most of the data collected are made publically available in the form of a set of web-based interactive tools collectively labelled NASCIS (National Adult Social Care Intelligence Service).[b] In the 2011 data collection information was collected on five primary client types in the age range 18-64: physical disability (including sensory impairment); mental health; learning disability; substance misuse; other vulnerable people.

- The category of **physical disability** (including sensory impairment) appears to plausibly map onto the SEN categories of PD (physical disability), VI (visual impairment), HI (hearing impairment), MSI (multiple sensory impairment).
- The category of **mental health** has no clear parallel in SEN classification. While some children with Behavioural Emotional and Social Difficulties may have mental health

[a] http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information
[b] https://nascis.ic.nhs.uk/

problems, the category is primarily used to identify children with behavioural difficulties. Indeed, the validity and utility of this category of SEN is currently under review.[27 28]

- The category of **learning disability** appears to plausibly map onto the SEN categories of MLD (moderate learning difficulty), SLD (severe learning difficulty) and PMLD (profound multiple learning difficulty).
- The categories of **substance abuse** and **other vulnerable people** have no parallels in SEN classification.

Given the lack of correspondence between the adult categories of mental health, substance misuse and other vulnerable people and SEN classification, it is not possible to use the process we have established for estimating future need for social care for these groups. As a result, we have focused on estimating future need for social care among people with **physical disability** (including sensory impairment) and people with **learning disability**. It should be noted that:

- 78% of gross social service expenditure in 2010/11 on working age adults was accounted for by services provided to these two client groups;[29]
- 63% of users of social care services in the 18-64 age range in 2010/11 were from these two client groups.[30]

People with Physical Disability

As described above, our process of estimating future need for social care for a given group of disabled adults involves the following six stages:

1 Ascertaining the number of children in England with SEN associated with the adult disability category in question from the latest available DfE School Census;
2 Adjusting these data for the effects of child mortality to estimate the number of children with SEN associated with the adult disability category in question who would reach 18 years of age between 2012 and 2030;
3 Appling estimates of the percentage of these children that are likely to become eligible for adult social care services under differing eligibility criteria;
4 Using information from the NHS Information Centre for Health and Social Care to estimate the number and age profile of disabled adults using social care services in 2011/12;
5 Adjusting the population of current adult service users for the expected effects of mortality over the period 2012-2030;
6 Combining these estimates with estimated inflows from child services to estimate net changes in need over the period 2012-2030.

Identifying Children with SEN Associated with Physical Disability

The DfE conducts a School Census that collects information on all children attending maintained and non-maintained special schools in England. It is estimated that this Census covers 97% of all English children of school age.[31] The pupil-level component of the 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 (if necessary) secondary type of SEN. The SEN categories include four categories that are associated with physical disability (including sensory impairment):

- PD – physical disabilities
- HI – hearing impairment
- VI – visual impairment
- MSI – multiple sensory impairment

From the spring 2011 School Census we calculated the number and percentage of children with PD, HI, VI and MSI among children who were 4-15 years old at the commencement of the school year. We excluded children younger than 4 years of age and children older than 15 years of age as the presence of SEN associated with physical disabilities is likely to be associated with both early school entry and leaving school at age 16.

As would be expected, prevalence rates for SEN 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). In the modelling contained in this report we made the assumption that prevalence rates of SEN associated with physical 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 2011 School Census.

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

- 5.0 for PD
- 2.8 for HI
- 1.6 for VI
- 0.3 for MSI

To avoid double counting (given that two categories of SEN can be recorded for each child): children with PD and either HI, VI or MSI were coded as having PD; and children with both HI and VI were coded as having MSI.

To test the validity of the identification of SEN associated with physical disabilities in these data, we examined the extent to which prevalence varied by gender and household poverty as previous epidemiological studies have suggested that both physical disabilities and sensory impairments are more likely among boys and poorer children.[32-40]

- All categories of the above categories of SEN were significantly more common among boys, with odds ratios[c] of 1.38 for PD, 1.06 for HI, 1.36 for VI and 1.44 for MSI.
- Household poverty was measured by child eligibility for free school meals. All categories of SEN were significantly more common among children in poorer households, with odds ratios of 1.74 for PD, 1.55 for HI, 1.66 for VI and 1.49 for MSI.

We derived estimates of the numbers of children with physical disabilities in each year age band from 0-17 by applying our prevalence estimates to current population projections of children in England.[19]

[c] A measure of the increased risk of disability associated with being male.

Estimating Child Mortality

The second stage of the process involved estimating the number of children with physical disabilities in England who would reach 18 years of age between 2012 and 2030. 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.

To this end we undertook a systematic review of the existing literature on mortality rates among people with impairments or health conditions associated with SEN or child disability. The review is included as Appendix 2. The literature in this area is surprisingly sparse, especially in relation to certain health conditions or impairments.[41 42] For example, in our review we were unable to identify any studies relating to mortality rates among people with visual impairment and only one study on mortality rates among people with hearing impairment (which reported no difference in mortality rates among people with hearing impairment when compared to the general population).[43] Several studies examined the life expectancy of people with cerebral palsy or spina bifida,[44-51] the results of which suggested the mortality rates in these two conditions may be 10 times greater than mortality rates observed in the general population. However, not all children with a SEN classification of physical disability will have cerebral palsy or spina bifida. The prevalence of cerebral palsy has recently been estimated at 2.1 per 1,000 live births[52] and the prevalence of spina bifida among 0-19 year old children at 0.3 per 1,000.[53] Given the evidence of significantly higher mortality rates among children with cerebral palsy a live birth prevalence of 2.1 per 1,000 should lead to a population prevalence rate at ages 7-15 of approximately 2.0. Thus if *all* children with cerebral palsy and spina bifida are identified as having SEN of physical disability, they would only constitute 46% (2.3 of 5.0 per 1,000) of the group of children identified as having a SEN of physical disability. Mortality rates among the other 54% of this group are unknown.

Given this information we have estimated the following base mortality rates.

- For children with SEN of physical disability or multi-sensory impairment we have assumed that mortality rates will be 7.5 times greater than general child mortality rates.
- For children with SEN of visual impairment or hearing impairment we have assumed that mortality rates will be 1.25 times greater than general child mortality rates; an increase reflecting the increased risk of mortality among boys and children living in poorer households.

Population child mortality rates were taken from the latest data available from the Office for National Statistics.[18] Child mortality has systematically decreased over the last decade, with an average annual reduction of between 0.6% and 4.0% depending on child age.[18] Given this, we assumed that SEN specific child mortality rates would continue to decline at a similar rate across the forecast period.

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

Not all young people with physical disabilities when transitioning from school 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 physical disabilities who are likely to meet differing levels of eligibility for adult social care.[15 16]
- The rationing of access to adult social care services by eligibility criteria.

As described above, in our previous work in this area we adopted a consultative approach to deriving estimates of eligibility for each type of SEN associated with physical disabilities. [9 12 13] In this project we derived estimates from fieldwork undertaken in six CASSRs (see Table 1, above). In this fieldwork, information on future eligibility was collected on less than 10 children with visual impairment or multi-sensory impairment. We have therefore assumed that eligibility for children with visual impairment would be identical to that for children with hearing impairment and for children with multi-sensory impairment would be identical to that for children with physical disability.

In addition to 'inflows' to social care associated with transition from children's services, people acquire physical disabilities in later life. Spinal cord injuries represent probably the most commonly acquired physical disability in early adulthood, with annual incidence rates of approximately 40 per million being reported, most of whom are young adults.[54] In our forecasting of need for adult social care among adults with physical disability we have, therefore, conservatively estimated that 400 people with newly acquired physical disability, primarily spinal cord injury aged 19-30 (total population estimate for 2012 of 10 million), will become users of adult social care services.

We used these estimates in the context of 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.[3] 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*[2], of adopting a more *preventative* approach to social care.[3-5] 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.

Estimating Attrition among Current Users of Adult Social Care Services

The most recent information available suggests that, in 2010/11, 189,830 adults with physical disabilities (including sensory impairments) aged 18-64 used adult social care services in England.[30] The available data do not, however, provide a breakdown of the age profile of the population of current users. To estimate this we applied an age-profile based on data collected in Wave 1 of the Office for Disability Issues new longitudinal *Life Opportunities Survey* (LOS).[1] Specifically we determined from LOS the age profile of the population of adults aged 18-64 who reported either an inability or severe difficulty in any one of the following areas: seeing; hearing; mobility; dexterity; breathing; or a result of a long-term health condition. We then applied this age profile to the total number of users reported by CASSRs to the NHS Information Centre. The resulting profile is shown below in Figure 2.

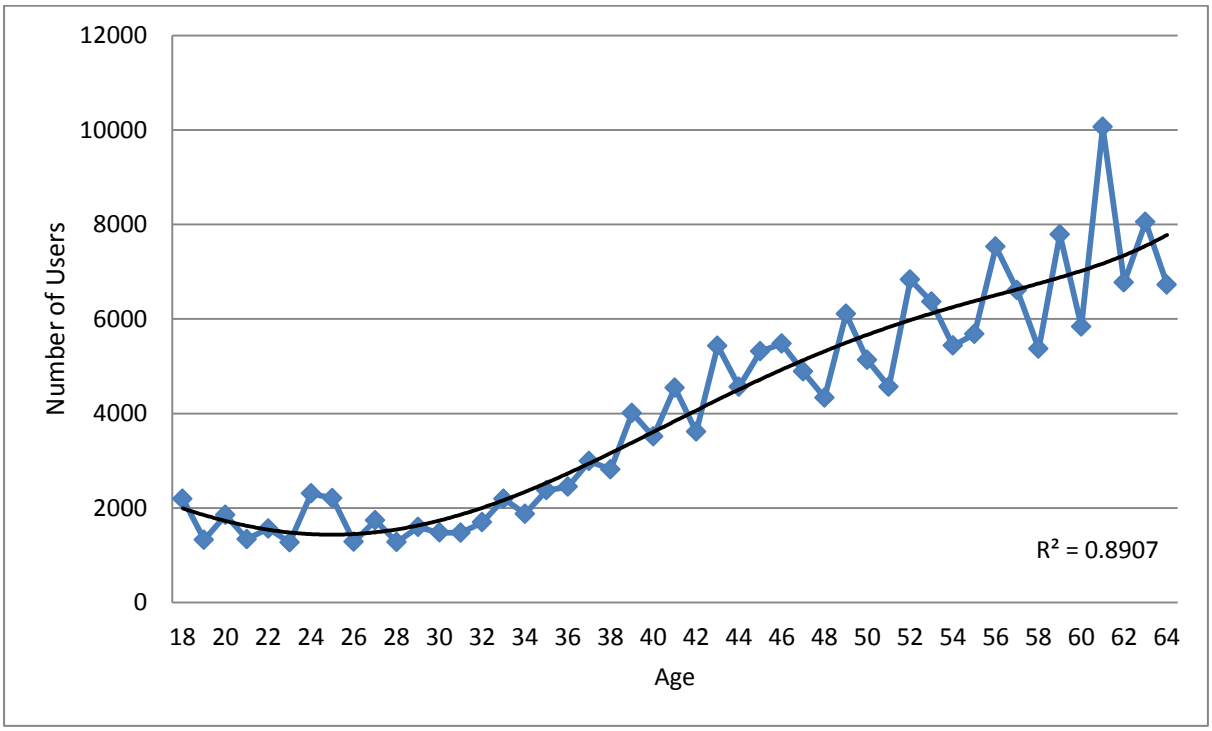

Figure 2: Estimated Age Profile of Current Users of Adult Social Care Services Aged 18-64 with a Primary Client Type of Physical Disabilities

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 2012-2030. The estimated increased relative risk of mortality used was identical to those applied to the child cohort (see above). Again, given that mortality rates are declining, we assumed that the annual rates of decline seen in the general population over the past decade would continue to apply to people with physical disabilities over the forecast period.

Estimating Net Changes in Adult User Population

In order to estimate net changes in the population of people with physical disabilities who use adult social care services we combined our estimates of inflows from children's services and inflows from acquired physical disability in early adulthood with our estimates of attrition in the cohort of current service users. Three estimates were generated, one for each of the three scenarios of rationing. Given the marked increase in serious disability with age (see Figure 2) after age 30,[1] we have restricted our projections to the age range 19-30. There is, at present, insufficient information to accurately predict the age-specific incidence of the onset of serious disability for older ages. However, such information will become available in the future with the release of subsequent waves of data from the longitudinal *Life Opportunities Survey*.[1]

Our projection for future need for social care services for adults with physical disabilities in England between the ages of 19 and 30 are presented below in Table 2. In this table we present for each year the estimated numbers of eligible adult users of social care services with physical disabilities and the annual percentage change from the previous year. Figure 3 presents the data contained in Table 2 in graphical form.

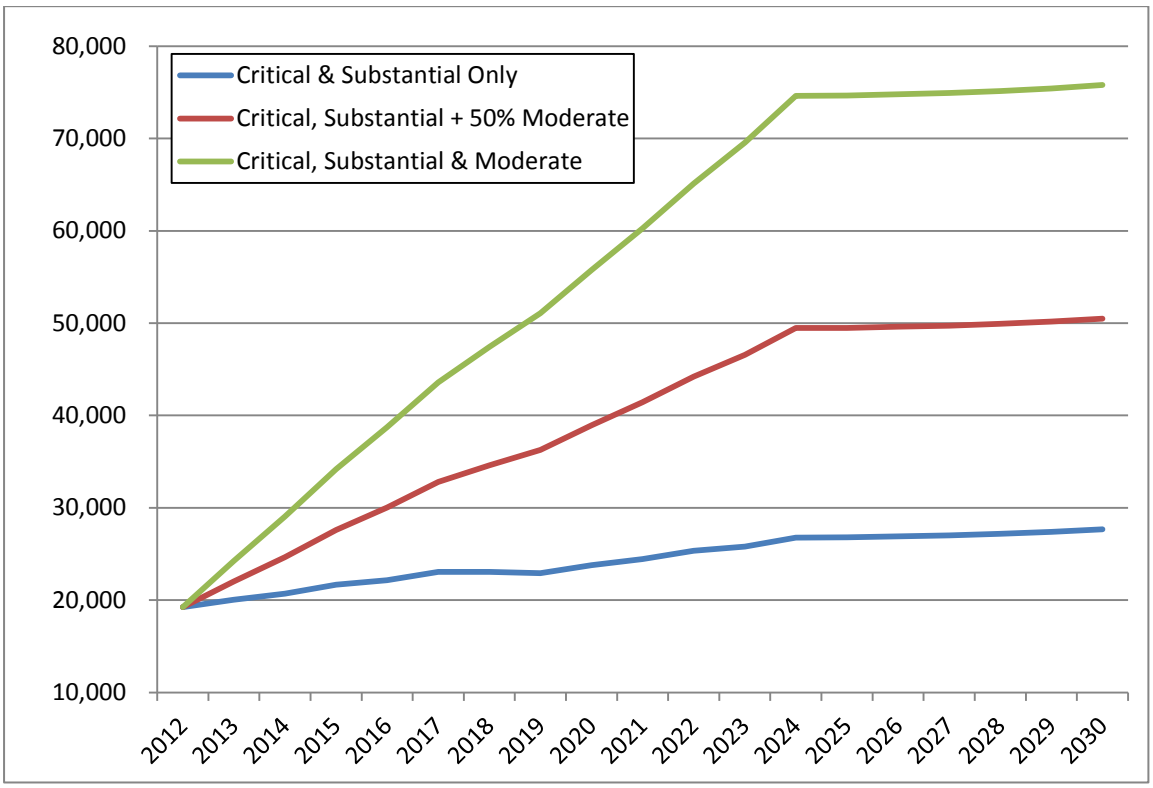

Figure 3: Estimated Number of Users of Adult Social Care with Physical Disabilities aged 19-30, 2012-2030

Table 2: Estimated Number of Users of Adult Social Care with Physical Disabilities and Annual Percentage Change 2012-2030						
	Critical or Substantial Need		Critical, Substantial and 50% of People with Moderate Need		Critical, Substantial or Moderate Need	
Year	Estimated Number of Users	Annual % Change	Estimated Number of Users	Annual % Change	Estimated Number of Users	Annual % Change
2012	19,237		19,237		19,237	
2013	20,031	4%	22,033	15%	24,254	26%
2014	20,693	3%	24,665	12%	29,071	20%
2015	21,676	5%	27,613	12%	34,199	18%
2016	22,162	2%	30,013	9%	38,721	13%
2017	23,075	4%	32,805	9%	43,597	13%
2018	23,054	0%	34,619	6%	47,443	9%
2019	22,917	-1%	36,276	5%	51,086	8%
2020	23,794	4%	38,947	7%	55,743	9%
2021	24,437	3%	41,422	6%	60,250	8%
2022	25,350	4%	44,214	7%	65,126	8%
2023	25,795	2%	46,552	5%	69,565	7%
2024	26,782	4%	49,462	6%	74,608	7%
2025	26,807	0%	49,493	0%	74,644	0%
2026	26,915	0%	49,619	0%	74,789	0%
2027	27,012	0%	49,733	0%	74,919	0%
2028	27,172	1%	49,918	0%	75,131	0%
2029	27,380	1%	50,161	0%	75,408	0%
2030	27,658	1%	50,484	1%	75,776	0%
Compound Annual Growth Rate		1.8%		4.7%		6.5%

All three scenarios suggest sustained growth in the need for social care services for younger adults with physical disabilities over the period 2012-2030. Compound annual growth rates vary from 1.8% to 6.5%. All estimates show a decelerating trend in the rise in need with little change in the period 2025-2030. During this period all users in the 19-30 age group will have been aged under 18 at the start of the forecasting period. As such, any changes simply reflect changes in overall birth rates.

These estimates would involve providing support to between an additional 6,000 to 46,000 young adults with physical disabilities over the next ten years, resulting in a ten year growth rates of 32% to 239%.

A 'no growth' scenario in the number of users of adult social care services for young adults with physical disabilities could only be achieved by either cutting services to existing users or by rationing access to services to young adults with physical disabilities with 'critical' need and 61% of those with 'substantial' need.

Selected Characteristics of Young People with Physical Disabilities Entering Adult Social Care Services

The characteristics of new entrants to adult social care will depend on the assumptions used in the estimates. In Table 3 we provide a breakdown of selected characteristics of predicted new entrants to adult social care with physical disabilities between 2012 and 2024 if services are provided to new entrants with critical or substantial need and 50% of potential new entrants with moderate need. As can be seen, just over one in five new entrants will be from a British minority ethnic community and around one in four from a poor household or deprived community.

Table 3: Selected Characteristics Of Predicted New Entrants with Physical Disability To Adult Social Care, 2012-2024

Disability	
Physical Disability	87%
Hearing Impairment	5%
Vision Impairment	3%
Multiple Sensory Impairment	4%
Indicators of Household and Area Deprivation	
Eligible for Free School Meals	26%
Lowest IDACI Quintile	23%
Ethnic Group	
African	2%
Caribbean	1%
Other Black Background	<1%
Chinese	<1%
Bangladeshi	1%
Indian	2%
Pakistani	6%
Other Asian Background	1%
Gypsy/Romany	<1%
Irish	<1%
Traveller of Irish Heritage	<1%
White British	79%
Other White Background	3%
White and Asian	1%
White and Black African	<1%
White and Black Caribbean	1%
Other Mixed Background	1%

People with Learning Disability

As described above, our process of estimating future need for social care for a given group of disabled adults involves the following six stages:

1 Ascertaining the number of children in England with SEN associated with the adult disability category in question from the latest available DfE School Census;
2 Adjusting these data for the effects of child mortality to estimate the number of children with SEN associated with the adult disability category in question who would reach 18 years of age between 2012 and 2030;
3 Appling estimates of the percentage of these children that are likely to become eligible for adult social care services under differing eligibility criteria;
4 Using information from the NHS Information Centre for Health and Social Care to estimate the number and age profile of disabled adults using social care services in 2011/12;
5 Adjusting the population of current adult service users for the expected effects of mortality over the period 2012-2030;
6 Combining these estimates with estimated inflows from child services to estimate net changes in need over the period 2012-2030.

Identifying Children with SEN Associated with Learning Disability

The DfE conducts a School Census that collects information on all children attending maintained and non-maintained special schools in England. It is estimated that this Census covers 97% of all English children of school age.[31] The pupil-level component of the 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 (if necessary) 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 would be classified in SEN categories as having specific learning difficulties (SPLD). ASD is not synonymous with learning disabilities. However, 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,[55-57] the combination of ASD and MLD/SLD/PLMD was relatively rarely recorded in the data.

From the spring 2011 School Census we calculated the number and percentage of children with MLD, SLD, PMLD and ASD among children who were 4-15 years old at the commencement of the school year. 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). 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 2011 School Census.

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

- 34.4 for MLD
- 4.7 for SLD
- 1.2 for PMLD
- 10.9 for ASD

These estimates are broadly consistent with the findings of epidemiological studies of the prevalence of learning disabilities and ASD among children.[55-62] 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 household poverty as both are common findings in epidemiological studies of the prevalence of learning disabilities.[55-62]

- All categories of SEN associated with learning disabilities were significantly more common among boys, with odds ratios[d] of 1.83 for MLD, 1.82 for SLD, 1.24 for PMLD and 5.61 for ASD.
- Household poverty was measured by child eligibility for free school meals. All categories of SEN associated with learning disabilities were significantly more common among children in poorer households, with odds ratios of 3.03 for MLD, 2.55 for SLD, 1.91 for PMLD and 1.39 for ASD.

In our estimates of the numbers of children with learning disabilities, we included children with recorded SEN of MLD, SLD or PMLD and 32% of children with recorded SEN of ASD (this figure takes into account that 18% of children with ASD had also been identified in the data as having learning disabilities). 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.[19]

[d] A measure of the increased risk of disability associated with being male.

Estimating 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 2012 and 2030. 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.[63 64] 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[65] and that exposure to poverty is associated with increased child mortality,[66] 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.[64] Population child mortality rates were taken from the latest data available from the Office for National Statistics.[18]

For children with SLD we estimated mortality rates on the basis of information extracted from the Sheffield Learning Disability Case Register on child mortality over the last decade.[e] For children with PMLD we estimated annual mortality rates to be 50% higher than the rates estimated for children with SLD.[63]

The estimates we used for 2012 were (per year per 1,000 children):

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

Child mortality has systematically decreased over the last decade, with an average annual reduction of between 0.6% and 4.0% depending on child age.[18] Given this, we assumed that SEN specific child mortality rates would continue to decline at a similar rate across the forecast period.

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

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.[15 16]
- The rationing of access to adult social care services by eligibility criteria.

As described above, in our previous work in this area we adopted a consultative approach to deriving estimates of eligibility for each type of SEN associated with learning disabilities. [9 12 13] In this project we derived estimates from fieldwork undertaken in six CASSRs (see Table 1, above).

We used these estimates in the context of 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.[3] 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*[2], of adopting a more *preventative* approach to social care.[3-5] 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.

Estimating Attrition among Current Users of Adult Social Care Services

The most recent information available suggests that, in 2010/11, 142,455 adults with learning disabilities used adult social care services in England.[30] This estimate is lower than the estimate of 189,000 adults with learning disabilities known to health and social care services[67] 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,[f] the City of Manchester and the Metropolitan Borough of Stockport.

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

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 2012-2030. 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.[68] These mortality estimates (presented in Table 4) 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.[18] The markedly greater death rates among people with learning disabilities apparent in these figures is consistent with that reported in previous research studies.[14 68] Again, given that mortality rates are declining in the general population and among people with learning disabilities,[14-18] we assumed that the annual rates of decline seen in the general population over the past decade would continue to apply to people with learning disabilities over the forecast period.

Table 4: Age-Specific Mortality Estimates 2012-2030

Age Group	20-29	30-39	40-49	50-59	60-69	70-79	80-89	90+
Annual mortality rate (per 1,000)								
2012	3.96	5.01	7.48	19.21	31.52	72.27	131.37	285.71
2030	2.87	4.41	6.16	13.18	17.71	40.21	88.47	208.82

Estimating Net Changes in the 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. Three estimates were generated, one for each of the three scenarios of rationing.

Our projections for future need for social care services for adults with learning disabilities in England are presented below in Table 5. In this table we present for each year the estimated numbers of eligible adult users of social care services with learning disabilities and the annual percentage change from the previous year. Figure 4 presents the data contained in Table 5 in graphical form.

Table 5: Estimated Number of Users of Adult Social Care with Learning Disabilities and Annual Percentage Change 2012-2030

	Critical or Substantial Need		Critical, Substantial and 50% of People with Moderate Need		Critical, Substantial or Moderate Need	
Year	Estimated Number of Users	Annual % Change	Estimated Number of Users	Annual % Change	Estimated Number of Users	Annual % Change
2012	142,455		142,455		142,455	
2013	146,591	2.9%	147,405	3.5%	148,220	4.0%
2014	150,708	2.8%	152,332	3.3%	153,957	3.9%
2015	154,710	2.7%	157,130	3.1%	159,550	3.6%
2016	158,701	2.6%	161,916	3.0%	165,131	3.5%
2017	162,487	2.4%	166,473	2.8%	170,458	3.2%
2018	166,114	2.2%	170,853	2.6%	175,592	3.0%
2019	169,551	2.1%	175,021	2.4%	180,491	2.8%
2020	172,802	1.9%	178,982	2.3%	185,163	2.6%
2021	176,041	1.9%	182,933	2.2%	189,825	2.5%
2022	179,432	1.9%	187,056	2.3%	194,680	2.6%
2023	182,995	2.0%	191,375	2.3%	199,754	2.6%
2024	186,577	2.0%	195,715	2.3%	204,853	2.6%
2025	190,329	2.0%	200,191	2.3%	210,102	2.6%
2026	194,266	2.1%	204,870	2.3%	215,579	2.6%
2027	198,457	2.2%	209,832	2.4%	221,371	2.7%
2028	202,589	2.1%	214,724	2.3%	227,087	2.6%
2029	206,804	2.1%	219,703	2.3%	232,901	2.6%
2030	211,103	2.1%	224,774	2.3%	238,820	2.5%
Compound Annual Growth Rate		2.0%		2.4%		2.7%

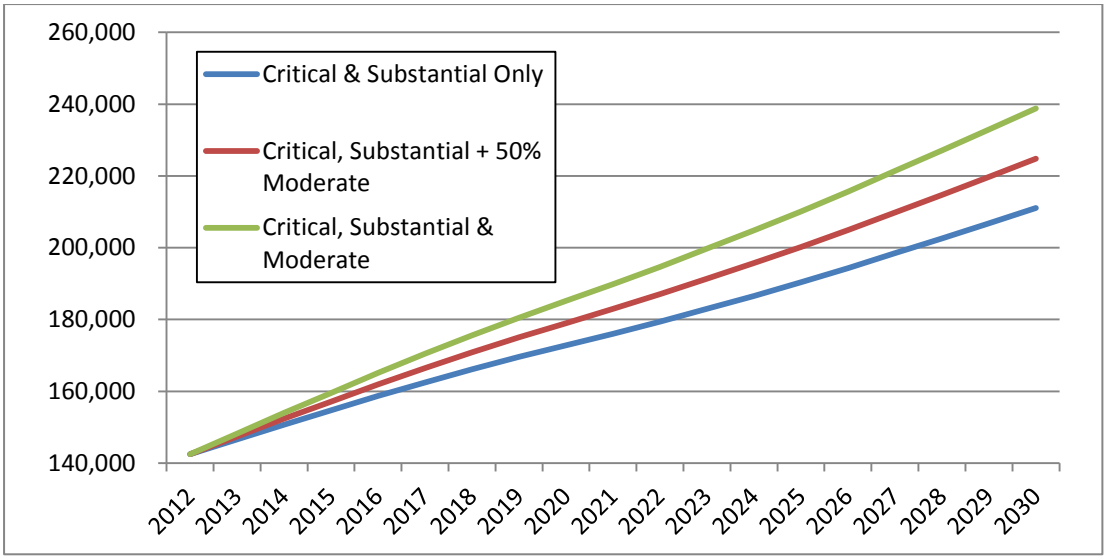

Figure 4: Estimated Number of Users of Adult Social Care with Learning Disabilities 2012-2030

All three scenarios suggest sustained growth in the need for social care services for adults with learning disabilities over the period 2012-2030. Estimated annual increases vary across time from 1.9%-2.9% (services only provided to new entrants with critical or substantial needs) to 2.5%-4.0% (services are provided to new entrants with critical, substantial or moderate needs). Compound annual growth rates vary from 2.0% to 2.7%.

These estimates would involve providing support to between an additional 37,000 to 52,000 adults with learning disabilities over the next ten years, resulting in a ten year growth rate of 26% to 37%. For all estimates the annual percentage growth rate slows from 2013 to 2022 at which point it stabilises. This pattern reflects changes in birth rates over the last two decades.

A 'no growth' scenario in the number of users of adult social care services for people with learning disabilities could only be achieved by either cutting services to existing users or by rationing access to services to young people with learning disabilities with 'critical' need and 25% of those with substantial need.

Selected Characteristics of Young People with Learning Disabilities Entering Adult Social Care Services

The characteristics of new entrants to adult social care will depend on the assumptions used in the estimates. In Table 6 we provide a breakdown of the severity of learning disability and ethnicity (as recorded in the School Census) of predicted new entrants to adult social care with learning disabilities between 2012 and 2030 if services are provided to new entrants with critical or substantial need and 50% of potential new entrants with moderate need. As can be seen, 25% of predicted new entrants belong to British minority ethnic communities and a substantial minority will be from deprived households and/or deprived neighbourhoods.

Table 6: Severity Of Learning Disability And Ethnicity Of Predicted New Entrants To Adult Social Care, 2012-2030

Severity of Learning Disability	
Mild/Moderate	59%
Severe	30%
Profound Multiple	11%
Indicators of Household and Area Deprivation	
Eligible for Free School Meals	36%
Lowest IDACI Quintile	29%
Ethnic Group	
African	3%
Caribbean	2%
Other Black Background	1%
Chinese	<1%
Bangladeshi	2%
Indian	2%
Pakistani	5%
Other Asian Background	1%
Gypsy/Romany	1%
Irish	<1%
Traveller of Irish Heritage	<1%
White British	75%
Other White Background	3%
White and Asian	1%
White and Black African	<1%
White and Black Caribbean	1%
Other Mixed Background	1%

Summary & Comments

The aim of the project was to estimate changes in the need for social care services for adults with disabilities in England between 2012 and 2030. The project built upon and extended our previous work on estimating future need for social care services among adults with learning disabilities.[9-13] The latest update of our previous work suggested that there will be sustained growth in the need for social care services for adults with learning disabilities over the time period 2011-2030, with estimated average annual increases varying from 1.2% to 5.1% (average 3.2%).[13] These estimates were marginally lower than, but not as varied as, those we produced in 2008.[9]

Our previous approach was, however, based on a number of assumptions, some of which we believe to be highly robust, some less so.[13] The most critical source of uncertainty in the model was in the validity of our estimates of the likely eligibility for social care services for new entrants at different levels of 'need',[25 26] especially for potential new entrants with less severe disabilities. In our previous work we used estimates developed through a process of consultation with relevant stakeholders (primarily disabled people's organisations and field agencies). One of the key aims of the present project was to test out and refine these assumptions through field-based research. Other aims of the present project were to:

- update the estimates based on revised information;
- extend the model to other adults with disabilities.

Our proposed primary research involved attempting to collect information on the assessed level of eligibility for samples of 50 children aged 14-16 identified as having SEN in 10 CASSRs. In order to compensate for potential drop out we initially recruited 18 CASSRs who all indicated a strong commitment to participating in the project. Unfortunately, the fieldwork took place during 2010/11, a period of unprecedented turmoil within CASSRs in England. Despite extending the period of data collection by several months, only six CASSRs were able to provide any data and only two CASSRs were able to provide data on the target sample of 50 children. As a result, we were only able to collect information on 223 young people (45% of the target sample).

Given the difficulties we encountered in our field work, we agreed with NIHR SSCR that we would also undertake some exploratory analyses of the association between SEN and the experimental disability statistics collected by DfE in Spring 2011. The aim of these analyses was to explore the relationship between SEN and disability (as defined under the Equality Act 2010) and to determine whether this information could be used to strengthen the estimates of assessed level of need for adult social care services. Unfortunately, the results of these analyses suggested that the disability data collected by the DfE were subject to a number of serious biases associated with social exclusion and socio-economic position that made their use untenable in the present project.

We were, however, able to use the new field-generated estimates of eligibility to: (1) update our previous work on estimating future need for adult social care services for people with learning disabilities; and (2) extend this work to estimating future need for adult social care services for people with physical disabilities (including sensory impairment) in the age range 19-30. To estimate future need beyond this age point would require making important assumptions about the annual

age-specific incidence (onset) of serious physical and sensory impairments in adults. There is, at present, insufficient information to make these assumptions with any degree of confidence. However, such information will become available in the near future with the release of Wave 2 data from the Office for Disability Issues' longitudinal *Life Opportunities Survey*.[1]

All of the scenarios included in our estimation procedures suggested sustained growth in the need for social care services for adults with physical or learning disabilities over the time period 2012-2030.

- For younger adults with physical disabilities compound annual growth rates vary from 1.8% to 6.5%. A 'no growth' scenario in the number of users of adult social care services for young adults with physical disabilities could only be achieved by either cutting services to existing users or by rationing access to services to young adults with physical disabilities with 'critical' need and 61% of those with 'substantial' need.
- For adults with learning disabilities compound annual growth rates vary from 2.0% to 2.7%. A 'no growth' scenario in the number of users of adult social care services for adults with learning disabilities could only be achieved by either cutting services to existing users or by rationing access to services to young people with learning disabilities with 'critical' need and just 25% of those with substantial need.

As we have argued above, rationing social care to people with critical or substantial needs is inconsistent with the policy objective strongly emphasised in *Putting People First*[2], of adopting a more *preventative* approach to social care.[3-5]

Our estimates are based on a number of assumptions, some we believe to be highly robust, some less so. In Table 7 we list the key assumptions and data sources used and indicate the degree of confidence (from low 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 7: 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 and physical disabilities estimated from 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 disabilities	Moderate	Low
Age-specific mortality estimates for adult with learning disabilities using social care services	Moderate	Low
Age-specific mortality estimates for adult with physical disabilities using social care services	Low	Low
Estimates of eligibility for new entrants with disabilities	Moderate	Moderate

As in our previous work, 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.

There are a number of factors that would have an impact on future need that we were not able to 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 disability over time. We do not feel that there are sufficient grounds for building in estimates of changes in the incidence of disability. Factors that are likely to lead to an increase in the incidence of disability 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 disabilities, reductions in child poverty rates and improvements in early years services. The net effect of these competing pressures on the incidence of child disability 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 disabilities over time. Current trends suggest that mortality rates among people with disabilities should continue to fall (as they are expected to do in the general population). It is not possible, however, to 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 fall at the same rate as they have in the general population over the past decade. 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[6]
- Increasing rates of maternal employment[6]
- Increases in the percentage of older people with learning disabilities (whose parents are likely to have died or be very frail)[7 8]
- Changing expectations among families regarding the person's right to an independent life.

Appendix 1: Analysis of DfE Disability Data

Given the difficulties we encountered in our planned field work, we also investigated the association between SEN and the experimental disability statistics collected by DfE in Spring 2011. The aim of these analyses was to explore the relationship between SEN and disability (as defined under the Equality Act 2010) and to determine whether this information could be used to strengthen the estimates of assessed level of need for adult social care services.

DfE guidance states that, under the Equality Act 2010, schools, Local Authorities and the DfE need to collect information on child disability so that they can better understand the nature of the disabled pupil population for whom they are responsible and to help in planning and monitoring provision and improving outcomes. As a result, collection of disability data was carried out on a voluntary basis as part of the Spring School Census in 2011.

A toolkit was made available to help schools work with parents to better identify and support children with disabilities.[g] Previous DfE funded research had suggested that use of the toolkit could improve the provision of information on the needs of disabled children and their families and help schools to better meet their duties under disability and equality legislation.[69] While multiple entries to record a child with more than one disability were allowable in the experimental data collection, only the child's primary (first recorded) disability was included in the released data file.

Experimental disability information was collected in 2011 on 284,687 out of 7,522,853 pupils in maintained schools and non-maintained special schools (3.8% of the total pupil population). These data were matched to other data from the National Pupil Database (e.g, age, gender, ethnicity, school characteristics) for 7,476,636 pupils (99% of the main pupil file and 93% of pupils for whom disability information was collected). The prevalence of specific impairments did not differ between the matched and unmatched files. Table 1 provides information on the prevalence of children's primary impairments in the matched file.

[g] http://www.education.gov.uk/childrenandyoungpeople/specialeducationalneeds/a0065985/disability-toolkit

Table 1: Prevalence of Impairments in Matched File		
	N	%
Learning	11282	4.3%
Other Disability/health problem	6672	2.5%
Behaviour	6827	2.6%
Communication	5015	1.9%
Diagnosed with autism or Asperger's	4890	1.9%
Mobility	1693	0.6%
Vision	1540	0.6%
Hearing	2238	0.8%
Personal care	132	0.0%
Medication	985	0.4%
Incontinence	443	0.2%
Eating & Drinking	586	0.2%
Hand function	460	0.2%
Consciousness	184	0.1%
Disabled under DDA but not in above categories	110	0.0%
None	220972	83.7%
Total Collected	264029	
Total	7476636	

Potential Biases in the Collection of Disability Data

The majority of schools (89%) returned either no disability data or disability data on all pupils, indicating the possibility of bias by type of school. That 11% of schools collected some but incomplete data indicates the possibility of bias associated with pupil characteristics. As a result we examined a number of possible sources of bias. These analyses indicated higher return rates for disability data:

- in primary schools (4.7-4.8%) than secondary schools (1.8-1.9%);
- in special schools (12.7% v 3.4%);
- for boys than girls (3.6% v 3.4%);
- among Asian, Black and 'Mixed' ethnic groups (3.9-4.8%) than Chinese or White (3.0-3.2%);
- among children eligible for Free School Meals (4.6% v 3.3%);
- in more deprived areas (5.2% v 3.1%);
- among boarders (20%) than non-boarders (3.5%);
- among children with SEN (3.1% none, 3.9% School Action, 5.0% School Action+, 10.1% Statement).

In multivariate analyses gender, ethnicity and Free School Meal eligibility had no meaningful association with returns of child disability data. However, increased rates of data collection were apparent in more deprived areas (OR 1.5-2.6), special schools (OR 1.6), primary schools (OR 2.6) and boarding schools (OR 4.6).

The Association between SEN and Disability

Not all children with SEN would be classed as disabled under the Equality Act 2010. Similarly, not all children who would be classed as disabled under the Equality Act 2010 have SEN.[69-71] In this section we explore the association between SEN and child disability. First (in Table 2) we compare the overall prevalence of different categories of SEN and categories of impairment associated with child disability.

As can be seen, where categories can be matched, the observed prevalence rates for categories of child disability tend to lie in between those reported for categories of SEN recorded at School Action Plus level or above and with Statements.[72]

Table 2: The Prevalence of Disability & Primary SEN in Subsample For Who Disability Information Was Collected

Disability	Primary SEN	Disability	Primary SEN (School Action Plus or Statement)	Primary SEN (Statement)
Learning	Total	4.3%	5.9%	2.5%
	MLD		4.1%	1.5%
	SLD		1.4%	1.2%
	PMLD		0.5%	0.5%
	SPLD		1.6%	0.4%
Behaviour	BESD	2.6%	4.2%	1.6%
Communication	SLCN	1.9%	4.4%	0.8%
Diagnosed with autism or Asperger's	ASD	1.9%	2.5%	2.0%
Mobility	PD	0.6%	1.5%	1.0%
Vision	VI	0.6%	0.6%	0.6%
Hearing	HI	0.8%	0.9%	0.5%
	MSI		0.1%	0.1%
Disabled under DDA but not in above categories/other	OTH	2.5%	1.0%	0.4%
Any		**16.3%**	**17.3%**	**8.0%**

Note: MLD moderate learning difficulty, SLD severe learning difficulty, PMLD profound multiple learning difficulty, SPLD specific learning difficulty, BESD behavioural emotional social difficulty, SLCN speech language and communication needs, ASD autism spectrum disorder, PD physical disability, VI visual impairment, HI hearing impairment, MSI multiple sensory impairment, OTH other

However, examination of the association between SEN and disability within individual children reveals a very different picture. Overall:

- 55% of children who were identified as being disabled had also been identified as having a SEN (School Action Plus or Statement);
- 52% of children who were identified as having a SEN (School Action Plus or Statement) had also been identified as being disabled.

Low levels of agreement were also evident for specific categories of SEN/disability.

- Autism/ASD
    - 70% of children who were identified as having a disability associated with Autism had also been identified as having a SEN (School Action Plus or Statement) of ASD;
    - 52% of children who were identified as having a SEN (School Action Plus or Statement) of ASD were identified as having a disability associated with Autism.

- Learning Difficulties
    - 31% of children who were identified as having a disability associated with Autism had also been identified as having a SEN (School Action Plus or Statement) of ASD;
    - 22% of children who were identified as having a SEN (School Action Plus or Statement) of ASD were identified as having a disability associated with Autism.

These discrepancies may reflect that SEN and disability are simply different constructs.[69-71] However, closer inspection of the experimental disability data casts doubt on its validity. First, Figure 1 shows the percentage of pupils with specific categories of SEN (primary or secondary) and who have a Statement of SEN who were recorded as being disabled.

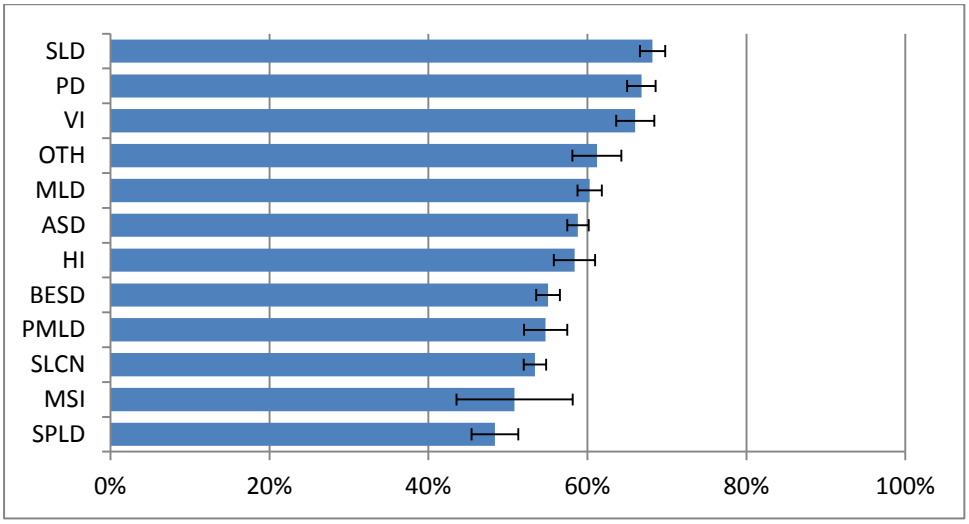

Figure 1: Percentage of Pupils with SEN (Primary or Secondary) with Statements of SEN Who Were Recorded as Being Disabled (with 95% Confidence Intervals)

There are a number of worrying anomalies in these results.

- First, pupils with Profound Multiple Learning Difficulties are significantly less likely to be recorded as being disabled than either pupils with Severe Learning Difficulties or pupils with Moderate Learning Difficulties;
- Second, pupils with Multiple Sensory Impairments (typically children who have impairments of both vision and hearing) are significantly less likely to be recorded as being disabled than pupils with Visual Impairments.

Given these anomalies, we undertook additional analyses to cast further light on the validity of the DfE disability data. These involved examining the association between the reported prevalence of disability and neighbourhood and household deprivation and school type.

The Association between Neighbourhood and Household Deprivation and Disability

There is extensive evidence to suggest that most impairments that are associated with child disability and child SEN are socially patterned, with higher risk (prevalence) being observed in poorer households and more socially and environmentally deprived communities.[31-40 73-87]

There were, however, some marked differences in the strength of association between indicators of poverty/area deprivation and the reported prevalence of SEN and disability as recorded in the 2011 School Census. First, Figure 2 shows the association between household poverty (indicated by eligibility for free school meals) and the prevalence of any SEN/disability and the two most common forms of SEN/disability (behavioural and learning). As can be seen, for all categories the magnitude of the increased risk associated with living in a poorer household was markedly (and statistically significantly) greater for SEN than disability data.

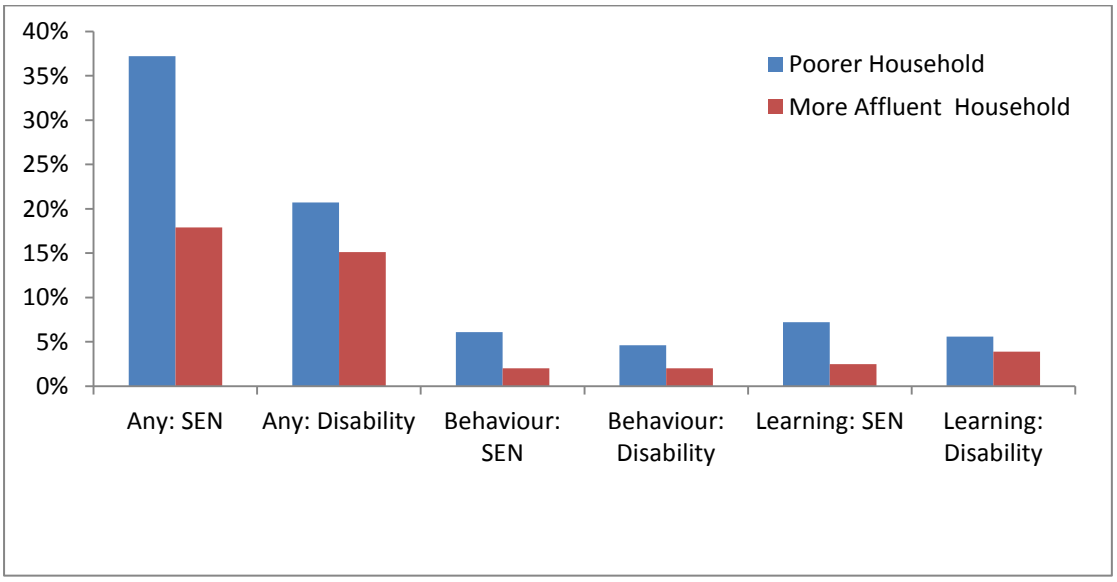

Figure 2: The Association between Household Poverty (Indicated By Eligibility for Free School Meals) and the Prevalence of Any SEN/Disability and SEN/Disability Associated with Learning and Behaviour

Second, Figure 3 shows the association between area deprivation (indicated by national IDACI decile[88] and the prevalence of any SEN/disability and SEN/disability associated with learning difficulties. As can be seen, while the prevalence of SEN was clearly associated with neighbourhood deprivation, there was (surprisingly) little association between neighbourhood deprivation and disability. Indeed, for both categories of disability prevalence was higher in the most affluent 10% of neighbourhoods in England than in the poorest 10% of neighbourhoods. Such a pattern of the distribution of disability is highly inconsistent with current evidence.

Finally, we examined whether there was any association between area deprivation and whether children with SEN would be identified as disabled. Children living in more deprived communities were **less likely** to be coded as disabled than children living in more affluent communities for the SEN categories of Autism Spectrum Disorders (53% v 65%; OR 0.62, 95%CI 0.56-0.69); Behavioural Social and Emotional Difficulties (46% v 51%; OR 0.84, 95%CI 0.78-0.91); Profound Multiple Learning Difficulties (47% v 59%; OR 0.61, 95%CI 0.48-0.77); Speech Language and Communication Needs (36% v 48%; OR 0.62, 95%CI 0.57-0.67); Severe Learning Difficulties (63% v 69%; OR 0.76, 95%CI 0.65-0.89); and Specific Learning Difficulties (39% v 48%; OR 0.69, 95%CI 0.60-0.80).

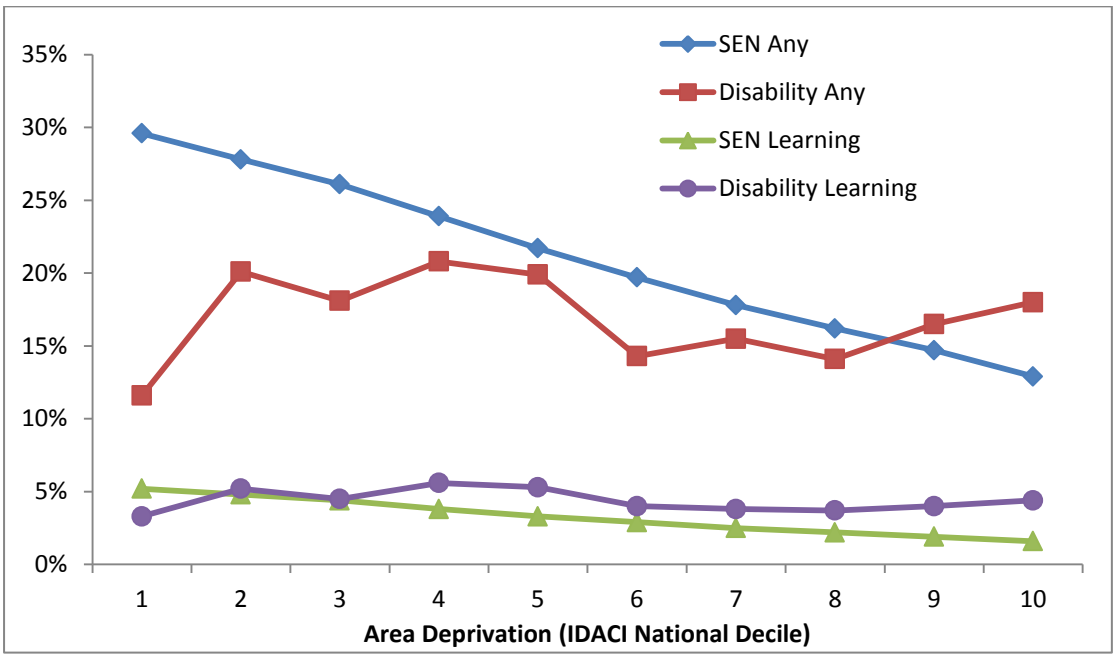

Figure 3: The Association between Area Deprivation (Indicated By IDACI Decile) and the Prevalence of Any SEN/Disability and SEN/Disability Associated with Learning

The Association between School Type, Disability & SEN

Special Schools

- For some categories of SEN (measured at School Action Plus or Statement) children attending special schools were **less likely** to be coded as disabled than children attending mainstream schools. This pattern was evident for the SEN categories of: Autism Spectrum Disorder (disability coding 55% in special schools v 67% in mainstream schools, OR 0.58, 95%CI 0.53-0.64); Hearing Impairment (43% v 72%; OR 0.29, 95%CI 0.24-0.35); Physical Disability (51% v 75%; OR 0.34, 95%CI 0.26-0.39); Specific Learning Difficulties (34% v 47%; OR 0.58, 95%CI 0.44-0.77); and Visual Impairment (57% v 71%; OR 0.55, 95%CI 0.44-0.68).
- That children with SEN attending special schools with some forms of SEN were coded as *less* disabled than those in mainstream schools is highly unlikely to reflect any underlying differences in the severity of child impairment (which is likely to be more severe in children attending special schools). More plausibly, it may reflect the less normative expectations and environment provided by segregated special schools.

Boarders

- For some categories of SEN (measured at School Action Plus or Statement) children attending boarding schools (many of which were residential special schools) were **less likely** to be coded as disabled than children attending day schools. This pattern was evident for the SEN categories of: Autism Spectrum Disorder (21% v 64%; OR 0.15, 95%CI 0.11-0.20); Behavioural Emotional and Social Difficulties (29% v 50%; OR 0.41, 95%CI 0.34-0.50); Hearing Impairment (31% v 66%; OR 0.23, 95%CI 0.17-0.30), MLD (29% v 53%; OR 0.37, 95%CI 0.27-0.50); Profound Multiple Learning Difficulty (15% v 59%; OR 0.13, 95%CI 0.07-0.22); Speech Language and Communication Needs (11% v 45%; OR 0.15, 95%CI 0.11-0.20); Severe Learning Difficulty (26% v 70%; OR 0.16, 95%CI 0.11-0.22); and Specific Learning Difficulties (13% v 46%; OR 0.17, 95%CI 0.07-0.41).
- That children with SEN attending residential (typically special) schools were coded as *less* disabled than those in mainstream schools is also unlikely to reflect any underlying differences in the severity of child impairment (which is likely to be more severe in children attending residential schools). More plausibly, it may reflect the less normative expectations and environment of segregated residential special schools.

Conclusions

The previous sections cast severe doubt on the validity of the disability data collected by SEN:

- There is very low agreement between SEN and disability associated with similar impairments (e.g., learning);
- Pupils with more severe impairments (e.g., Profound Multiple Learning Difficulties) are significantly less likely to be recorded as being disabled than pupils with less severe impairments (Severe Learning Difficulties, Moderate Learning Difficulties);
- The distribution of disability across neighbourhoods of varying wealth/deprivation is highly inconsistent with current evidence on the epidemiology of impairments and disability;
- Children in more segregated and atypical settings (special schools, residential schools) are significantly less likely to be recorded as disabled than children in more normative settings.

Taken together these results suggest that the disability data collected by the DfE are subject to a number of biases associated with social exclusion and socio-economic position that makes their use untenable in the present project. Indeed, due to the low uptake of the disability data collection DfE has indicated that pupil disability data will not be collected in the 2013 School Census but will be replaced by mandatory data collection post-2013 based on a new standard, yet to be developed and agreed by their Information Standards Board.

Appendix 2: Mortality in Conditions Associated with Childhood Disability or Special Educational Needs: A Systematic Literature Review

Introduction

This review aims to summarise the existing literature which contributes to knowledge on mortality rates for children and younger adults with disability or special educational needs (SEN) in the United Kingdom (UK), including physical or sensory impairments, health conditions associated with a high risk of disability and mental health problems. It was evident from the outset that such information was unlikely to be available for some conditions associated with childhood disability or special education needs (SEN). In a review of the world literature on life expectancy for people with disabilities, it was noted that: "The world literature since 1966 on the subject of life expectancy in people with disabilities is surprisingly sparse" p201.[42] Thomas & Barnes (2010) identified approximately 120 articles worldwide on aspects of life expectancy in relation to physical and cognitive disability. Similarly, a review of English language studies in relation to survival in children and youth with chronic health conditions found no information on survival for asthma, attention deficit hyperactivity disorder (ADHD), autistic spectrum disorder (ASD), depression, diabetes mellitus (I & II) and HIV/AIDS.[41] As the review in hand is restricted to studies which present information on mortality in the UK only, it was evident that information would be unavailable for further conditions. For example, in a summary of evidence on the health of people with autistic spectrum disorder (ASD), of three articles identified relating to mortality in people with ASD, none presented data in relation to the UK.[89]

This review focuses on studies which provide information on mortality rates compared to those in the general population via use of standardised mortality ratios (SMRs). SMRs are calculated by the indirect method of standardisation.[90] The total number of observed deaths in the target population or sample of interest (e.g. people with intellectual disabilities) is divided by the number of deaths that would be expected based on death rates of a chosen standard population, which is usually the relevant national or regional general population.[91] The resulting ratio of observed/expected deaths is often multiplied by 100 so that it is expressed as a percentage. In this review, where SMRs in results were presented as percentages these have been converted by dividing by 100. Hence, an SMR of 1.0 indicates that there is no difference between the death rates of the target population and the general population. SMRs of greater than one indicate that the death rate was higher in the target population than in the general population, and SMRs of less than one indicate that the death rate was lower in the target population than in the general population. Where possible, 95% confidence intervals are also presented. SMRs can be considered statistically significant at $p<.05$ if the 95% confidence interval does not include 1 (unity).

Method

Electronic literature searches were conducted using PubMed (which includes Medline, preMEDLINE and other related databases) in August 2011 to identify relevant peer reviewed articles published from 1990 onwards in the English language. Terms for conditions associated with childhood disability or SEN were combined with search terms relating to mortality (e.g. survival, death, mortality, life expectancy).

All articles identified by searches were assessed for their relevance to the review objectives firstly by reading abstracts. If abstracts were unavailable, or did not provide enough detail to assess the relevance of the article, the full text of the article was obtained and relevance assessed from this. All relevant studies were included in the review regardless of methodological quality, although studies were categorised by research design in order to illustrate the overall number of studies identified in relation to established hierarchies of evidence.[92] The inclusion and exclusion criteria are outlined below.

Inclusion criteria

- 1990 to present
- Peer reviewed literature
- English language
- Samples exclusively from the UK or mixed samples where figures for UK presented separately
- Containing data pertaining to SMRs for children or adults with conditions related to childhood disability or special educational needs, including physical or sensory impairments, health conditions associated with a high risk of disability and mental health problems.

Exclusion criteria

- Pre-1990
- Non-peer reviewed
- Not in English language
- Studies on selected causes of death with no all cause mortality data
- Studies not reporting SMRs (eg reporting survival rates)
- Studies not reporting results for the UK separately
- Conditions with late onset (ie not present in children or young adults) eg dementia
- Conditions resulting from late onset condition eg dysphasia and dysphagia as result of stroke
- Acute conditions/short term outcomes (eg acute head injury, cardiac arrest)
- Neonatal mortality ie mortality associated with preterm birth
- Health conditions unrelated to disability or special educational needs (eg coeliac disease, haemophilia)
- Studies involving carriers of conditions only (eg carriers of Duchenne and Becker muscular dystrophy)
- Meeting abstracts, letters or comments.

Search Strategy

Using the limits: Humans, English, Publication Date from 1990 to 2011

The core search string used was: ("Morbidity"[Mesh]) OR ("Life Expectancy"[Mesh]) OR ("Death"[Mesh]) OR ("Survival"[Mesh]) OR ("Mortality"[Mesh]) AND ("Great Britain"[Mesh])

These were combined with the terms:

- "Disabled Persons"[Mesh]
- Specific learning difficulty
- moderate learning difficulty
- severe learning difficulty
- PMLD
- disab* (3688 hits, thus restricted to disab* and UK)
- autis* (high number of hits, restricted to autis* and uk)
- Cognitive Impairment
- Intellectual impairment
- Dexterity Impairment
- hearing Impairment (high number of hits, restricted to hearing Impairment and UK(
- Mobility impairment
- visual Impairment and uk
- Speech and Language
- Deaf-Blind
- Hand Tremors
- Reduced co-ordination
- Reduced Strength
- Repetitive Strain Injury
- Deaf
- Hard of hearing
- Learning Disability
- Attention Deficit
- ADD
- ADHD
- Dyscalculia
- Dysgraphia
- Dyslexia
- Non-Verbal
- Blindness
- Colour Blindness
- Low Vision
- Cerebral Palsy
- Spinal dysraphism

- Developmental disabilities
- Mental disorders diagnosed in childhood
- Language development disorders
- Nervous system diseases
- "Genetic Diseases, Inborn"[Mesh]
- "Developmental Disabilities"[Mesh]
- "Color Vision Defects"[Mesh] AND "Blindness, Cortical"[Mesh] AND "Blindness"[Mesh] AND
- "Deaf-Blind Disorders"[Mesh]
- "Hearing Loss"[Mesh]
- "Mental Retardation"[Mesh]
- “Fragile X Syndrome"[Mesh]
- "Communication Disorders"[Mesh]
- "Cerebral Palsy"[Mesh]
- "Ocular Motility Disorders"[Mesh]
- "Stereotypic Movement Disorder"[Mesh]
- "Sleep-Wake Transition Disorders"[Mesh]
- "Movement Disorders"[Mesh]
- "Epilepsy"[Mesh]
- "Brain Injuries"[Mesh]
- "Blindness"[Mesh] AND "Leber Congenital Amaurosis"[Mesh]
- "Amblyopia"[Mesh]
- "Anencephaly"[Mesh]
- "Heart Septal Defects, Atrial"[Mesh]
- "Celiac Disease"[Mesh]
- "Dystonia"[Mesh] AND "Dystonic Disorders"[Mesh]
- "Encephalitis"[Mesh]
- "Endocardial Cushions"[Mesh] AND "Endocardial Cushion Defects"[Mesh]
- "Fetal Alcohol Syndrome"[Mesh]
- "Fragile X Syndrome"[Mesh]
- "Guillain-Barre Syndrome"[Mesh]
- "Muscular Dystrophies"[Mesh]
- "Ectromelia"[Mesh]
- "Rickets"[Mesh]
- "Rehabilitation of Speech and Language Disorders"[Mesh] AND "Language Development
- Disorders"[Mesh]
- "Spinal Dysraphism"[Mesh]
- "Muscular Atrophy, Spinal"[Mesh] AND "Spinal Muscular Atrophies of Childhood"[Mesh]

Data Extraction & Synthesis

Data were extracted from the full text of articles identified as meeting the inclusion criteria. Textual descriptions were produced for each study which included bibliographic details, the geographical area within which the study took place, details of the condition(s) included in the study, details of the sample size and characteristics, study design and data sources, main results in relation to SMRs, and issues raised in the discussion. This information was also tabulated. A separate table was constructed which included available SMRs for all age bands for which figures were given in the article.

Results

A total of 28 studies were identified which presented SMRs in relation to conditions associated with disability or SEN, including physical or sensory impairments, health conditions associated with a high risk of disability and mental health problems, in children or younger adults. These studies are summarised in Tables A1 and A2. The conditions covered by the studies included: epilepsy;[93-100] intellectual disabilities;[101-106] mental illness,[107-112] including one study looking at children and adolescents prescribed antipsychotic medication;[113] neural tube defects;[114] people with attention deficit hyperactivity disorder (ADHD) in receipt of drug treatment;[115] osteogenesis imperfect;[116] Turner syndrome;[117] Klinefelter syndrome;[118] juvenile parkinsonism;[119] and chronic juvenile arthritis.[120]

In addition, further research was identified in relation to life expectancy which has not been included in the review due to the presentation of data in a form which is not comparable with SMRs, such as studies reporting the percentage of people with a condition surviving to specific ages. In particular, a number of studies report the life expectancy of people with cerebral palsy;[44-49] Hemming et al (2006) present information on the relative risk of death compared to the general population for people with cerebral palsy, and whilst this is generally presented only graphically, it is noted that at age 25 a Bristol based cohort had an increased risk of death of over 10 times that of the general population. Two studies report findings from a prospective longitudinal cohort study of infants with spina bifida.[50 51] Oakeshott et al (2010) note that between the ages of 5 to 40 years, the death rate in their cohort of those with spina bifida was over 10 times the national average.

Finally, one study was identified in relation to mortality in a cohort of users of cochlear implants for profound deafness.[43] In this retrospective cohort study of 3,630 ascertained cases (1,779 adults and 1,851 children), cumulative mortality in the cohort was estimated with the Life Tables method of survival analysis and compared to cumulative mortality expected in the gender- and age-matched general population. Cumulative mortality for all causes among children did not differ significantly from values expected in the general population and for all causes among adults was numerically lower than values expected for the general population at all times after implantation, and was significantly lower at some times.

For studies where it has been possible to extract information on all-cause SMRs, the condition, overall numbers followed up, SMRs (by specific ages bands where possible) and number of deaths are given in Table A1. There are two exceptions. The first is a study on mortality in people with

intellectual disabilities which has not been included in the table.[106] In this study, SMRs are given by 18 quinquenniums (QQ) of birth (e.g., 1896-1900, 1901-1905) by gender, resulting in 36 SMRs. These ranged from 1.08 (0.43, 2.22) for males born 1906-1910 to 22.20 (6.05, 56.83) for males born 1971-1975, and 0.74 (0.30, 1.54) for females born 1906-1910 to 34.03 (9.28, 87.13) for females born 1971-1975. Overall, SMRs were mostly significantly greater than 1.0 suggesting that death rates in people with intellectual disabilities tend to exceed those in the general population.The second is a study which included people with juvenile parkinsonism (JP) as part of a larger study but the SMR for JP was based on only 4 people and 1 death resulting in a SMR of 3.2 with an extremely wide CI (0.08, 18.0).[119]

Study designs and data sources

The majority of studies employed a retrospective cohort design. There were a small number of prospective cohort studies. A series of studies have reported SMRs resulting from the National General Practice Study of Epilepsy (NGPSE) which is a prospective population based study of a cohort of 1091 patients diagnosed with epilepsy or possible epilepsy between 1984 and 1987.[93 95 98] Two studies report findings from a prospective cohort study of 370 people with schizophrenia who had contact with NHS psychiatric services in Southampton in 1981-1982.[109 110] One study was based on 101 children with epilepsy identified in the 1958 National Child Development Study (NCDS) followed up at age 33.[100]

The studies employed a range of data sources. Several studies were based on analysis of the General Practice Research Database (GPRD).[99 113-115] The GPRD data source contains anonymised primary care records for approximately 3.6 million patients (in the region of 5% of the UK population) from over 430 general practices.[99] Locally based registers formed another data source, including a Psychiatric Case Register,[108] and learning disability registers.[102 104-106] A number of studies drew their sample from specialist units or centres including cytogenetics centres,[117 118] genetic units,[101] specialist epilepsy residential care[94] and specialist epilepsy clinics.[121] Other studies used routinely collected hospital care records including Hospital Episode Statistics for England,[111 112] Scottish inpatient records[120] and inpatient admissions and outpatient appointments in an area of Wales as part of a range of data sources.[96 103] One study was based on secondary analysis of anonymised clinical records of 150,000 cases on the Case Register Interactive Search (CRIS) system.[107]. Finally, one study was based on a survey of patients in England and Wales from unspecified data sources.[116]

Condition Specific SMRs

In this section, information is presented on SMRs reported for specific conditions. However, this section should be read taking into account the limitations outlined in the discussion section. For some conditions a number of studies have been conducted which give information on SMRs. Studies of epilepsy consistently report mortality rates significantly higher than those of the general population. These vary from 22.4 (18.9, 26.2) for 0-18 years olds with epilepsy receiving AEDs[99] to 1.7 (1.1, 2.4) for those in the NGPSE with definite epilepsy aged 70-79[95] and 1.57 (1.25, 1.97) for those with *possible* epilepsy also in the NGPSE cohort.[98] Where different age bands are reported, SMRs tend to be lower in the oldest age groups. For example, for those with definite epilepsy in the

NGPSE [95] SMRs were 5.4 (3.2, 8.4) for 0-49 year olds and 8.4 (5.3, 12.7) in 50-59 year olds, reducing to 1.7 (1.1, 2.4) in 70-79 year olds and 2.0 (1.5, 2.7) in those aged over 80.

A number of studies look at mental illness. Three studies involving cohorts with mental illness report SMRs for all diagnostic groups in the sample combined. The SMRs reported are: 1.65 (1.58, ng) for 0-84 year olds;[108] 2.15 (1.95, 2.36) for 15 to 65+ year olds;[107] and 6.42 (5.32, 7.68) for 10-19 year olds. In relation to specific diagnostic groups, for schizophrenia, SMRs indicate a mortality risk of around double that of the general population overall. The lowest SMR was for those aged 0-84 with schizophrenia and related illnesses [108] with a SMR of 1.59 (1.47, ng). The highest SMR was for inpatients aged 10-19 with schizophrenia which was 6.70 (4.25, 10.05)[111] reflecting a pattern of SMRs reducing with age. In a recent study of over 24,000 people with schizophrenia, one year following inpatient care, the SMR for all ages combined was 2.2 (2.0, 2.4).[112] However, SMRs reduced with age from 6.2 (ng) for those under 45 to 3.9 (ng) for those aged 45-64 and 2.0 (ng) for those aged 65-84.

Two studies report SMRs for bipolar disorder.[107 112] In both studies, mortality overall is nearly double that of the general population, with higher SMRs in younger age groups. In the largest study which involved 9,086 people with bipolar disorder, the SMR for all age groups combined was 1.9 (1.6, 2.2), with the rate being 3.4 (ng) for those aged under 45, 2.6 for those aged 45-64 and 1.8 for those aged 65-84. Overall, in all studies looking at mental illness reporting separate age bands, SMRs reduced with age for all diagnostic categories.[107 108 112]

Reported SMRs for cohorts of people with intellectual disabilities varied widely from 1.51 (1.23, 1.83) for those aged 70+ with moderate to profound intellectual disabilities[105] to 18.0 (15.2, 20.9) for those on one learning disability register.[102] Where SMRs are reported by age bands these generally reduce with age, with the SMR for 20-29 year olds in Tyrer et al. (2007) being 11.50 (8.14, 15.78) compared to 1.51 for those aged 70+ (as noted above). One cohort with Down's syndrome had an overall SMR of 6.22 (5.59, 6.93).[101] Only one study reported a non significant SMR for people with intellectual disabilities [103] which was 1.82 (0.93, 2.71).

In relation to ADHD, one study looked at patients aged 2 to 21 who had received drug treatment for ADHD[115] and found no significant difference in mortality rates overall (SMR 1.44 (0.58, 2.96)) although there was an increased risk of suicide. Secondly, in a study of adolescents one year post discharge from inpatient psychiatric admission [111] figures are given for ICD codes F90-99 (behavioural and emotional disorders with onset usually occurring in childhood and adolescence) including ADHD, conduct disorders and emotional disorders specific to childhood. For this diagnostic group (aged 10-19) the SMR was 7.99 (3.45, 15.74).

One study presents information relevant to ASD. In the study of adolescents one year post discharge from inpatient psychiatric admission[111] figures are given for ICD codes F80-89 (disorders of psychological development) including Autism, pervasive developmental disorders, Rett's syndrome and Asperger's syndrome. For this diagnostic group (aged 10-19) the SMR was 30.17 (17.58, 48.31). SMRs for other conditions which are not the subject of multiple studies can be found in Table A1, including osteogenesis imperfect,[116] Turner syndrome,[117] Klinefelter syndrome,[118] juvenile chronic arthritis [120] and neural tube defects.[114]

Discussion

Notwithstanding the limitations outlined below, where information exists for the UK it is evident that there is an increased risk of mortality compared to the general population for a number of conditions associated with disability or special educational needs (SEN), including physical or sensory impairments, health conditions associated with a high risk of disability and mental health problems. The mortality risk associated with epilepsy is mainly reported to be around two to three times that of the general population. The mortality risk associated with mental illness is mainly reported to be around double that of the general population. For intellectual disabilities, the reported mortality risk varies, with the largest and most recent study suggesting a mortality risk of nearly threefold that of the general population.[104] The results for ADHD are mixed, with one study finding no difference to the general population [115] and one reporting a SMR of nearly 8, although the diagnostic category included other behavioural disorders in addition to ADHD and had a more limited age range of 10-19.[111] This latter study also provides the only available data with regards to ASD (indicating an extremely high SMR of over 30), although again the age range is limited and the diagnostic category also includes Rett's syndrome.

Finally, some information can be taken from studies which do not present SMRs. Only one study was identified in relation to hearing impairments based on a cohort of users of cochlear implants for profound deafness which reported no increased risk of mortality compared to the general population.[43] Similarly, studies have been identified in relation to life expectancy for those with cerebral palsy[44-49] and spina bifida[50 51] where SMRs are not given, but an increased risk of over 10 times that of the general population is noted for both cerebral palsy[48] and spina bifida.[51]

There are a number of limitations in the interpretation of SMRs included in this review. Firstly, many of the cohorts used are historical with dates of birth stretching back to, for example, the 1920s.[101] In some cases it is likely that treatment for conditions has improved markedly over time, with results not generalising to more recent patients. As noted by Hermon et al (2001), overall survival showed marked improvements for successive birth cohorts, particularly at young ages.[122] Secondly, the denominator for SMRs (expected number of deaths) can be very small for younger age groups, meaning that a small number of deaths in cohorts can lead to high SMRs.[111] This may account for some of the effect of age, for example Ackers et at (2011) suggest that the presence of the highest SMRs in those aged 2-11 compared to other age groups may be due to low general population denominators. However, the general trend of lower SMRs for the oldest age groups may also be partly accounted for by a 'healthy survivor' effect. In addition, small cohorts can lead to unstable estimates of SMRs with wide confidence intervals. Finally, some cohorts are highly selected groups, for example one study involves a cohort of people with severe and chronic epilepsy in a long term residential care unit which the authors note is not representative of the generality of patients with epilepsy.[94] Other limitations to cohorts include, for example, Hospital Episode Statistics not including independent sector admissions,[111] and only including people with a condition who have come to clinical diagnosis.[118] The diagnostic groupings are also not mutually exclusive, for example the prevalence rate of epilepsy amongst people with intellectual disabilities has been reported as at least 20 times higher than for the general population.[123]

Where SMRs are significantly greater than unity, the issue of the cause of excess mortality is important and this is addressed by many of the studies in this review but it has not been possible to include this information in this review. Suggested reasons for excess mortality include for example: unhealthy lifestyle (particularly high levels of smoking) and failed recognition and poor treatment of medical disease, or poor treatment compliance for people with schizophrenia;[109 110] suicide, accidents, violence and lifestyle factors for people with severe mental illness, substance use disorder or depression;[107] circulatory disease and respiratory disease in people with schizophrenia and bipolar disorder;[112] increased risk of suicide in people with ADHD;[115] underlying primary illness and/or inadequate management of underlying medical conditions in children prescribed antipsychotic medication;[113] and for people with intellectual disabilities, less than optimal medical care and lack of health promotion [102] and deaths due to preventable causes such as respiratory infections, circulatory system diseases and accidental deaths.[104]

It has not been possible to identify any information on mortality for a number of conditions. Firstly, no studies have been found in relation to mortality in children and younger adults with visual impairments, with existing research being limited to late onset visual impairment, for example Thiagarajan et al 2005.[124] Further, whilst in some instances studies exist in relation to specific conditions associated with physical disability such as neural tube defects,[114] it is not possible to ascertain SMRs for the broader group of people with physical disabilities generally. No information was identified in relation to mortality for the following categories of SEN: specific learning difficulties; speech, language and communication needs; and multisensory impairments. It may be possible for future research to address these gaps in knowledge with regards to mortality using the methodologies and data sources identified in the studies of other conditions, such as use of the GPRD.

Table A1: Summary of SMRs Reported in Studies by Reported Age Bands

Author	Date	Condition	Overall numbers followed up	Age band	SMR (& 95% CI)	Number of deaths
Ackers	2011	Epilepsy receiving AEDs	6,190	0-18 <2 2-11 12-18	22.4 (18.9, 26.2) 20.9 (13.2, 31.3) 42.4 (33.3, 53.2) 13.8 (10.4, 18.0)	151 16 76 59
Baxter	1996	All on Salford Psychiatric Case Register (PCR)	6,753	0-84 15-19 80-84	1.65 (1.58, ∞[h]) 8.70 (ng[i]) 1.24 (ng)	1,533 ng ng
Baxter	1996	Schizophrenia & related illnesses	1,398	0-84	1.59 (1.47, ∞)	462
Baxter	1996	Affective disorders	3,273	0-84	1.66 (1.56, ∞)	747
Baxter	1996	Neuroses	942	0-84	1.22 (1.05, ∞)	110
Baxter	1996	Personality disorders	778	0-84	2.07 (1.77, ∞)	117
Baxter	1996	Salford PCR but diagnostic group not known	203	0-84	2.56 (2.02, ∞)	55
Baxter	1996	Salford PCR but no psychiatric disorder	159	0-84	2.06 (1.57, ∞)	42
Brown	2000	Schizophrenia	370 (353 traced)	16-65	2.98 (2.36, 3.72)	79
Brown	2010	Schizophrenia	370 (363 traced)	16-65 in 1981-1982	2.89 (2.47, 3.37)	164
Chang	2010	Severe mental illness (any)	11,035[j]	15-65+ 15-44 45-64 65+	2.15 (1.95, 2.36) 4.47 (3.49, 5.64) 3.10 (2.61, 3.66) 1.60 (1.40 1.82)	446 71 140 235
Chang	2010	Schizophrenia	7,022	15-65+ 15-44 45-64 65+	2.25 2.01, 2.51 4.73 (3.52, 6.22) 3.44 (2.82, 4.16) 1.63 (1.39, 1.89)	322 51 106 165

[h] ∞ = upper CI not given due to one sided nature of hypothesis

[i] ng = not given

[j] Total for schizophrenia, schizoaffective disorders & bipolaraffective disorder but double counting due to some participants having more than one diagnosis

Author	Date	Condition	Overall numbers followed up	Age band	SMR (& 95% CI)	Number of deaths
Chang	2010	Schizoaffective disorders	1,313	15-65+ 15-44 45-64 65+	2.52 (1.83, 3.39) 3.96 (1.81, 7.52) 2.71 (1.48, 4.55) 2.10 (1.30, 3.21)	44 9 14 21
Chang	2010	Bipolar affective disorders	2,700	15-65+ 15-44 45-64 65+	1.95 (1.60, 2.35) 4.09 (2.38, 6.54) 2.58 (1.77, 3.64) 1.51 (1.15, 1.95)	108 17 32 59
Chang	2010	Substance use disorders	10,927	15-65+ 15-44 45-64 65+	4.17 (3.75, 4.64) 6.81 (5.77, 7.98) 4.40 (3.70, 5.20) 1.91 (1.44, 2.48)	348 153 139 56
Chang	2010	Depressive episode/recurrent depressive disorder	11,697	15-65+ 15-44 45-64 65+	1.29 1.19, 1.40 3.21 (2.40-4.20) 1.75 (1.35, 2.22) 1.18 (1.08, 1.28)	620 53 66 501
Chin	2011	Epilepsy (onset <=age 16)	101	Up to age 33	3.1 (1.1, 6.1)	10
Cockerell	1994	Epilepsy (definite)	564	0-80+ 0-49 50-59 60-69 70-79 80+	3.0 (2.5, 3.7) 7.6 (4.2, 12.5) 8.6 (4.7,14.1) 3.6 (2.2, 5.5) 1.9 (1.2, 2.8) 2.6 (1.8, 3.6)	114 15 15 21 26 37
Cockerell	1994	Epilepsy (definite or possible)	792	0-80+ 0-49 50-59 60-69 70-79 80+	2.5 (2.1, 2.9) 6.1 (3.4, 9.9) 6.6 (3.8, 10.5) 3.0 (1.8, 4.4) 2.1 (1.4, 2.9) 1.9 (1.4, 2.5)	150 16 17 24 38 55
Hermon	2001	Down's syndrome	1425	DOBs <1920 to <1990	6.22 (5.59–6.93)	346
Hoang	2011	Schizophrenia (2006 data)[k]	24,205 people discharged	All <45 45-64 65-84	2.2 (2.0, 2.4) 6.2 ng 3.9 ng 2.0 ng	376 ng ng ng
Hoang	2011	Bipolar disorder (2006 data)	9,086 people discharged	All <45 45-64 65-84	1.9 (1.6, 2.2) 3.4 ng 2.6 ng 1.8 ng	148 ng ng ng

[k] Most recent year reported only. Study also reports values for each year from 1999-2005.

Author	Date	Condition	Overall numbers followed up	Age band	SMR (& 95% CI)	Number of deaths
Hollins	1998	ID (Wandsworth)	1081	All on LD register from 1982-1990	9.6 (7.9, 11.4)	116
Hollins	1998	ID (Kensington, Chelsea, Westminster)	945	All on LD register from 1982-1990	18.0 (15.2, 20.9)	154
James	2010	Adolescent psychiatric inpatients (SMRs for individual diagnostic groups given below)	57,783 admissions	10-19	6.42 (5.32, 7.68)	120
James	2010	Schizophrenia	6,418 admissions	10-19	6.70 (4.25, 10.05)	23
James	2010	Affective disorders	6,151 admissions	10-19	9.40 (5.89, 14.23)	22
James	2010	Neurotic disorders	5,295 admissions	10-19	4.78 (2.06, 9.42)	8
James	2010	Eating disorders	3,028 admissions	10-19	11.03 (4.43, 22.73)	7
James	2010	Developmental disorders	2,317 admissions	10-19	30.17 (17.6, 48.3)	17
James	2010	Personality disorders	313 admissions	10-19	8.04 (2.01, 44.82)	1
James	2010	Behavioural disorders	3,566 admissions	10-19	7.99 (3.45, 15.74)	8
James	2010	Alcohol & substance abuse	30,695 admissions	10-19	3.81 (2.64, 5.33)	34
Klenerman	1993	Severe & chronic epilepsy (residential care)	Not stated (3,392 person years)	18-91	1.9 (1.6, 2.3)	113
Lawrenson	2000	Neural Tube defects	5,455	10-69 (1994) 10-69 (1995) 10-69 (1996) 10-69 (1997)	1.9 (0.8 - 3.8) 2.3 (1.1 - 4.5) 2.9 (1.2 - 5.8) 2.2 (0.6 - 5.9)	27 for 4 years combined
Lhatoo	2001	Epilepsy - definite	564	0-80+	2.6 (2.1, 3.0)	149

Author	Date	Condition	Overall numbers followed up	Age band	SMR (& 95% CI)	Number of deaths
				0-49 50-59 60-69 70-79 80+	5.4 (3.2, 8.4) 8.4 (5.3, 12.7) 3.1 (2.0, 4.5) 1.7 (1.1, 2.4) 2.0 (1.5, 2.7)	19 22 26 35 47
Lhatoo	2001	Epilepsy - definite or probable	792	0-80+ 0-49 50-59 60-69 70-79 80+	2.1 (1.8, 2.4) 4.2 (2.5, 6.4) 6.6 (4.2, 9.7) 2.7 (1.8, 3.8) 1.7 (1.2, 2.3) 1.6 (1.2, 2.0)	199 20 25 32 48 74
McCarthy	2009	ADHD receiving drug treatment: all cause mortality	5,351	2-21	1.44 (0.58, 2.96)	7
Morgan	2003	Intellectual disabilities (ID)	1,595	15-85+	1.82 (0.93, 2.71)	68
Morgan & Kerr	2002	Epilepsy	3007	All in geographical area	2.14 (1.74, 2.55)	109
Nashef	1995	Epilepsy (outpatients at specialist epilepsy clinics)	601	10-80	5.1 (3.3, 7.6)	24
Neligan	2011	Epilepsy (definite or possible)	792	Cohort established 1984-1987	2.21 (1.97, 2.47)	300
Neligan	2011	Epilepsy (definite)	564	Cohort established 1984	2.55 (2.24, 2.91)	225
Neligan	2011	Epilepsy (possible)	228	Cohort established 1984	1.57 (1.25, 1.97)	75
Neligan	2011	Febrile seizures	220	Cohort established 1984	0.34 (0.05, 2.39)	1
Paterson	1996	a. Osteogenesis imperfecta type IA	383	All ages	1.08 (0.64, 1.81)	a & b combined 31
Paterson	1996	b. Osteogenesis imperfecta types IB, IVA & IVB	237	All ages	1.93 (1.17, 3.13)	a & b combined 31
Paterson	1996	c. Osteogenesis imperfecta type III	123	All ages	Given in figure only	26
Rani	2011	Children &	2,767	<18 years	4.03 (1.48, 8.76)	6 out of

Author	Date	Condition	Overall numbers followed up	Age band	SMR (& 95% CI)	Number of deaths
		adolescents prescribed antipsychotic medication (excluding deaths due to pre-existing medical conditions)				30 included in analysis
Schoemaker	2008	Turner syndrome (affects females only)	3439	0-84 <15 15-44 45-84	3.0 (2.7, 3.4) 4.9 (3.2, 7.2) 3.9 (3.1,4.8) 2.6 (2.2, 3.0)	296 26 88 182
Swerdlow	2005	Klinefelter syndrome (affects males only)	3518	Year of birth <1930 to >1980	1.5 (1.4, 1.7)	461
Thomas	2003	Juvenile chronic arthritis (hospitalized) - male	499 (person-years at risk 4,396)	Mean age at admission 11.2	3.39 (1.97, 5.46)	17
Thomas	2003	Juvenile chronic arthritis (hospitalized) - female	747 (person-years at risk 6,619)	Mean age at admission 12.2	5.09 (3.19, 7.75)	22
Tyrer	2007	Moderate to profound ID	2,436	20+ 20-29 30-39 40-49 50-59 60-69 70+	3.24 (2.93, 3.56) 11.50 (8.14, 15.78) 8.45 (6.19, 11.27) 4.68 (3.41, 6.26) 5.59 (4.52, 6.83) 3.45 (2.75, 4.26) 1.51 (1.23-1.83)	409 38 46 45 95 85 100
Tyrer	2009	Moderate to profound ID	2,995	20+	2.77 (2.53, 3.03)	503

Table A2: Summary of Studies Included In Table of SMRs

Authors	Year	Geographical area	Condition related to disability	Sample Size & characteristics	Study Design & Method	Results	Comment
Ackers, Besag, Hughes, Squier, Murray & Wong	2011	UK	Epilepsy with prescribed antiepileptic drugs (AEDs)	6,190 children with epilepsy, aged <19 years who had been prescribed at least one AED in the period 1993-2005 and had a diagnosis of epilepsy or seizure.	Retrospective cohort study using the General Practice Research Database (GPRD)[I]. SMRs calculated based on UK general population mortality rates from the Office for National Statistics (ONS).	162 died, 11 of whom were excluded from the analysis (eg no epilepsy diagnosis, n=6). The overall SMR was 22.4 (95% CI 18.9-26.2).There were significant differences between the three age groups with SMRs being highest in children aged 2-11 years and lowest in those aged 12-18 years (differences probably due to general population denominators).	The majority of subjects died from non-epilepsy related causes (72.8%). Causality assessment results suggest that AEDs are not a major cause of death in children with epilepsy but appear to be associated with a small number of cases. For two subjects in was probable/likely that AED had caused death, and for three subjects it was possible that death was AED-associated.

[I] General Practice Research Database (GPRD) – this contains anonymised primary care records for approx 3.6 million people from over 430 general practices

Authors	Year	Geographical area	Condition related to disability	Sample Size & characteristics	Study Design & Method	Results	Comment
Baxter	1996	Salford	Diagnosis of schizophrenia or related illnesses, affective disorder, neurosis, or personality disorder	6,753 people on the Salford Psychiatric Case Register (PCR). Subjects censored at age 85 or above. Includes in-patients, out-patients and day patients receiving psychiatric or other mental healthcare, as well as those receiving social care support from the mental health department or attending a hostel or day centre.	Historical cohort design following up all those enrolled on PCR from 1968 to 1975. Follow up was done by 31st December 1990. Salford FPC Register and NHS Central Registry used to trace study population and cause of death obtained from death certificates. SMRs calculated based on death rates for population of Salford.	Of 6,753 in the cohort there were 1533 deaths (928 expected). Overall SMR of 1.65 (95% CI 1.58, ∞[m]). Age had a marked effect on mortality with rate ratios decreasing as age at enrolment increased. The highest rate ratio was 8.70 (age 15-19) lowest was 1.24 (age 80-84). Figures for other age groups are not presented. All-cause SMR was 1.75 for women and 1.55 for men.	During follow up there were 114 suicides of which 63 occurred in individuals diagnosed as having affective disorder.

[m] ∞ = upper CI not given due to one sided nature of hypothesis

Authors	Year	Geographical area	Condition related to disability	Sample Size & characteristics	Study Design & Method	Results	Comment
Brown, Inskip & Barraclough	2000	Southampton	Schizophrenia (in contact with NHS psychiatric services, living outside hospital)	370 people with schizophrenia aged 16-65 living outside hospital who had contact with NHS psychiatric services in 1981-1982. Mean age: men 39, women 43.	Prospective cohort study; record linkage with follow-up to December 1994. Mortality confirmed by death certificate or other official document confirming death.	Vital status know for 353 of cohort (96%). 79 deaths. SMR 2.98 (2.36, 3.72).	Cohort relatively small and some SMRs have wide CIs. Authors suggest that reasons for excess mortality include unhealthy lifestyle and failed recognition & poor treatment of medical disease, & poor treatment compliance. Results may not generalise to more recent patients.
Brown, Kim, Mitchell & Inskip	2010	Southampton	Schizophrenia (in contact with NHS psychiatric services, living outside hospital)	370 people with schizophrenia aged 16-65 living outside hospital who had contact with NHS psychiatric services in 1981-1982	Prospective cohort study; record linkage with follow-up to August 2006. Mortality data based on ONS database & confirmed by death certificate or other official document.	Vital status known for 363 of cohort (98%). 164 deaths. SMR 2.89 (2.47, 3.37). 95 deaths from diseases due to smoking.	Cohort recruited 25 years ago; outcomes may be different for people diagnosed more recently. Excess mortality may be due to smoking with 73% of cohort being smokers at outset of study.

Authors	Year	Geographical area	Condition related to disability	Sample Size & characteristics	Study Design & Method	Results	Comment
Chang, Hayes, Broadbent, Fernandes, Lee, Hotopf & Stewart	2010	South London & Maudsley (SLAM) NHS Trust (Lambeth, Southwark, Lewisham and Croydon) Covers approx 1.3 million.	Severe mental illness (SMI), substance use disorders & Depressive disorders	31,719 cases included with. All had contact with SLAM in study period & had received a SMI, substance use disorder, depressive episode or recurrent depressive disorders diagnosis during or before the study period. Age calculated as at 1st July 2008 and those under age 15 years excluded.	Secondary analysis of 150,000 anonymised electronic records accessed via Case Register Interaction Search System (CRIS). Identified using ICD-10 codes. Looked at mortality over a 3 year period 2007-2009. SMRs based on England and Wales mortality statistics for 2008.	Total of 1,370 deaths. Overall, SMRs were: any SMI = 2.15 (95% CI 1.95-2.36); substance use disorders = 4.17 (3.75-4.64); and depressive episode and recurrent depressive disorder = 1.29 (1.19-1.40).	Suggestions for higher mortality rates including suicide, accident, violence, and lifestyle factors influenced by the presence of SMI such as physical inactivity, poor nutrition, alchohol use, smoking, illicit drug use, plus rote of adverse effects of psychotropic medication. However, this study does not look at causal pathways.
Chin, Cumberland, Pujar, Peckham, Ross & Scott	2011	UK	Epilepsy with onset at or prior to age 16	101 children with epilepsy identified in the 1958 National Child Development Study (NCDS). 65 were followed up at age 33 and 10 had died.	Data linkage to National Statistics mortality registry, NCDS cohort flagged on death.SMR based on NCDS cohort without epilepsy.	10 deaths by age 33, SMR 3.1 (1.1, 6.1). Half of deaths were not 'from' epilepsy but from the underlying etiology.	Increased risk of death in adulthood for those with childhood epilepsy.

Authors	Year	Geographical area	Condition related to disability	Sample Size & characteristics	Study Design & Method	Results	Comment
Cockerell, Johnson, Sander, Hart, Goodridge & Shorvon	1994	UK - 275 General Practices	Epilepsy	Patients newly diagnosed with epilepsy or possible epilepsy between 1984 and 1987. A total of 1091 included, 564 with definite epilepsy, 228 with possible epilepsy, 220 with febrile convulsions, and 79 without epilepsy.	National General Practice Study of Epilepsy (NGPSE), a population based prospective study. Patients followed prospectively from the seizure which led to identification of epilepsy and flagged with the NHS Central Register for notification of death with cause of death taken from the death certificate. SMRs based on death rates for England and Wales.	161 people died, compared with 69 deaths that would have been expected. The SMR for definite epilepsy was 3.0 (2.5-3.7), & definite or possible epilepsy 2.5 (2.1-2.9). There were no deaths in the group with febrile convulsions.	Also looked at cause of death. They found a raised SMR for cancer, stroke and pneumonia.

Authors	Year	Geographical area	Condition related to disability	Sample Size & characteristics	Study Design & Method	Results	Comment
Hermon, Alberman, Beral & Swerdlow	2001	England and Scotland	Down's syndrome	1,425 individuals with Down's Syndrome (DS) born before 1990, earliest DS diagnosis 1959, latest 1990. 2% born before 1920, 11% before 1920-1939, 24% 1940-1959, 46% 1960-1969, 17% after 1969.	Sample drawn from 5 collaborating Genetic Units in England and Scotland. Mortality followed up via NHS Central Registers to July 1997.	Total of 346 deaths. For Down's Syndrome, all-cause death rate was 6 times the national population rate (SMR = 6.22, CI 5.59–6.93). Overall SMRs by 5 year age bands are presented graphically only. Overall survival showed marked improvements for successive birth cohorts, particularly at young ages.	As noted overall survival showed marked improvements for successive birth cohorts.

Authors	Year	Geographical area	Condition related to disability	Sample Size & characteristics	Study Design & Method	Results	Comment
Hoang, Stewart & Goldacre	2011	England	Schizophrenia & bipolar disorder	People admitted to inpatient care 1999-2006 with principal diagnosis of schizophrenia or bipolar disorder. Ages <45 to 84.	Retrospective data linkage. Hospital Episode Statistics for England linked to death certificate data. Extracted records of discharges from inpatient care from 1999-2006 where with either schizophrenia or bipolar disorder recorded as principal diagnosis. Obtained mortality date for one year following inpatient care.	Schizophrenia SMR 1.6 (1.5, 1.8) in 1999 and 2.2 (2.0, 2.4) in 2006. For bipolar disorder, SMR 1.3 (1.1, 1.6) in 1999 and 1.9 (1.6, 2.2) in 2006. Standardised mortality ratios were higher in younger than in older people	Natural causes, especially circulatory disease and respiratory diseases, were the main components of the increase in all cause mortality.

Authors	Year	Geographical area	Condition related to disability	Sample Size & characteristics	Study Design & Method	Results	Comment
Hollins, Attard, von Fraunhofer, McGuigan & Sedgwick	1998	London Boroughs of Wandsworth and Westminster, Kensington and Chelsea (KCW)	Intellectual disability	All people on two learning disability registers between 1982 and 1990 were identified, total of 2,026 people.	Retrospective cohort study. Death certificates were obtained for all those who had died between 1982 and 1990. SMRs were based on the death rate for the borough populations for Wandsworth and KCW separately.	For Wandsworth, the SMR was 9.6 (95% CI 7.9, 11.4). For KCW, the SMR was 18.0 (95% CI 15.2, 20.9). 30% of all deaths occurred in the under 50 age group. The most common cause of death was bronchopneumonia – 56 (48%) Wandsworth, SMR 74.1 (54.7, 95.6); 69 (45%) KCW, SMR 135.4 (103.5, 167.4).	They note that results suggest less than optimal medical care and need for improved health promotion and surveillance.
James, Clacey, Seagroatt & Goldacre	2010	England	Adolescent psychiatric inpatient admissions (excluding organic mental disorders and mental retardation – ICD codes F00-F09 & F70-F79)	10-19 year olds admitted to NHS hospitals with psychiatric condition as main diagnostic reason for admission	Analysis of Hospital Episode Statistics with hospital records linked to data from death certificates, with data on mortality available for one year post-discharge. Period covered 1998-2004.	120 deaths in the year following discharge. Overall SMR 6.42 (5.32, 7.67). SMRs were raised for all diagnostics groups except personality disorders where numbers too small to interpret.	Overall SMR six times that in general population of equivalent age. Baseline mortality in this age group is very low. No data on cause of death & independent sector admissions not included.

Authors	Year	Geographical area	Condition related to disability	Sample Size & characteristics	Study Design & Method	Results	Comment
Klenerman, Sander & Shorvon	1993	Chalfont Centre for Epilepsy, Gerrards Cross	Severe & chronic epilepsy in long term residential care unit	All patients at Chalfont Centre for Epilepsy with severe chronic epilepsy in the long term residential care unit over an 11 year period (total of 3,392 patient years). Mean age 52 (range 18-91 years).	Retrospective cohort study. Looked at all deaths between 1980 and 1990 & calculated SMRs.	There were a total of 113 deaths (SMR 1.9, 95% CI 1.6-2.3). Causes of death fell into 6 main categories, neoplasms (n=29, 26%), bronchopneumonia (n=28, 25%), circulatory diseases (n=27. 24%), seizure-related death (n=13, 12%); sudden unexpected death (SUD) (n=7, 6%), and accidents (n=3, 3%).	Retrospective study of highly selected group, not representative of generality of patients with epilepsy, with severe chronic epilepsy. Patients with rapidly progressive or neoplastic causes for epilepsy are not admitted so such cases excluded.
Lawrenson, Wyndaele, VlachonIkolis, Farmer & Glickman	2000	UK	Neural tube defects (NTD)	5,455 patients aged 10-69 on the 1994, 1995, 1996 and 1997 GPRD with diagnostic codes spina bifida, hydrocephalus, meningocele & meningomyelocele.	Cross-sectional. Patients with NTD in register identified. In each of the 4 study years the number of deaths in the general population & people with NTD were recorded. SMRs calculated against 1995 England & Wales population rates.	27 deaths in patients with NTD recorded. SMRs (95% CI): 1994 = 1.9 (0.8 - 3.8); 1995 = 2.3 (1.1 - 4.5); 1996 = 2.9 (1.2 - 5.8); 1997 = 2.2 (0.6 - 5.9).	Number of deaths each year was small so wide CIs. Increased risk of mortality of approximately double that in general population.

Authors	Year	Geographical area	Condition related to disability	Sample Size & characteristics	Study Design & Method	Results	Comment
Lhatoo, Johnson, Goodridge, MacDonald, Sander & Shorvon	2001	UK (NGPSE)	Epilepsy	NGPSE (c.f. Cockerell 1994) initially recruited 1091 patients between 1 and 90 years of age with newly diagnosed epilepsy from 275 general practices in England and Wales between 1984 and 1987. 792 patients with definite or probable epilepsy included in this follow-up	Ongoing, prospective population based study of the prognosis of epilepsy in 792 patients. Death flagged with ONS. Followed for up to 14 years (median 11.8 years).	17 (2%) untraceable. A total of 214 deaths, overall SMR of 1.9 (1.6, 2.2). For definite epilepsy, SMR 2.6 (2.1, 3.0). Probable epilepsy SMR 1.4 (1.0, 1.8). Definite or probable epilepsy SMR 2.1 (1.8, 2.4). No patients with febrile seizures died. Age specific mortality rates revealed significant increases in all age bands.	Results suggest an increased long-term mortality rate of twice that of the general population.

Authors	Year	Geographical area	Condition related to disability	Sample Size & characteristics	Study Design & Method	Results	Comment
McCarthy, Cranswick, Potts, Taylor & Wong	2009	UK GPRD	ADHD prescribed methylphenidate, dexamfetamine, or atomoxetine	5,351 patients aged between 2 and 21 years during the study period (1993-2006) with at least one prescription for methylphenidate, dexamfetamine, or atomoxetine	Retrospective cohort study using the GPRD. Patients followed from date of first prescription until date of death, age > 21 years, or the end of study period. SMRs based on data from ONS.	7 deaths. Due to small number of deaths, ethics did not permit reporting of SMRs by age and only total figures are reported. The SMR was 1.44 (0.58, 2.96) indicating that no difference was detected in mortality rates between the general population and the study cohort at $p < .05$. SMR for suicide in children aged 11-14 years (2 suicides) was 161.91 (19.61, 584.88); for those aged 15-21 (one suicide) the SMR for suicide was 1.84 (0.05, 10.25).	The study did not find increased risk of sudden death associated with ADHD drug treatment, however an increased risk of suicide was seen in the cohort. Other factors such as depression and antisocial behaviour frequently co-exist with ADHD which can predispose to teenage suicide.

Authors	Year	Geographical area	Condition related to disability	Sample Size & characteristics	Study Design & Method	Results	Comment
McGuigan, Hollins & Attard	1995	London Boroughs of Wandsworth Kensington Chelsea and Westminster.	Intellectual disability	Adults and children on the Learning Disability Registers of three London Boroughs in 1982. In 1990, there were 791 people of the Kensington, Chelsea and Westminster register and 965 on the Wandsworth register.	All deaths occurring between 1982 and 1990 were identified and death certificates obtained.SMRs were calculated for each quinquennium (QQ) of birth (eg 1896-1900, 1901-1905) by gender.	SMRs are given by 18 QQs of birth (eg 1896-1900, 1901-1905) by gender, resulting in 36 SMRs. These ranged from 1.08 (0.43, 2.22) for males born 1906-1910 to 22.20 (6.05, 56.83) for males born 1971-1975, and 0.74 (0.30, 1.54) for females born 1906-1910 to 34.03 (9.28, 87.13) for females born 1971-1975.	Conclude that death rates in the adult LD population exceed those in the general population.
Morgan & Kerr	2002	Cardiff and the Vale of Glamorgan, Wales	Epilepsy	3,007 patients with epilepsy identified as alive & resident in area with population of 434,000 on Jan 1st 1996 (all ages). Mortality data dawn from the Office of Population Studies for years 1993-1996.	Cross-sectional record linkage. Epilepsy register created using inpatient data (1991-1997), outpatient data (1991-1996) and mortality data (1993-1997). SMRs calculated (for 1996 deaths only) compared to the non-epilepsy population.	In 1996 there were 109 deaths of people with epilepsy. SMR 2.14 (CI, 1.74–2.55) for deaths in 1996.	SMR less than generally reported. Epilepsy may be less severe for this cohort which is based on a range of data sources than for cohorts solely from epilepsy clinic based sources.

Authors	Year	Geographical area	Condition related to disability	Sample Size & characteristics	Study Design & Method	Results	Comment
Morgan, Baxter & Kerr	2003	Cardiff & Vale of Glamorgan	Intellectual disability	1,595 people with ID aged 15-85+ identified from social services register, inpatient admissions & outpatient appointments	Retrospective cohort study. Looked at deaths between 1993 & 1996. Also looked at prevalence of epilepsy.	1,595 people with ID were identified of whom 16.1% had epilepsy. Between 1993 and 1996 there were 68 deaths, of which 16 (23.5%) were for those with co-existing epilepsy. This represents an insignificant SMR of 1.82 (0.93, 2.71).	For those with co-existing epilepsy, the mean age at death was 39.1 years for males and 44.8 years for females compared to 58.0 years and 60.6 years for those without epilepsy.
Nashef, Fish, Sander & Shorvon	1995	Specialist epilepsy clinics National Hospital for Neurology & Neurosurgery	Epilepsy (outpatients)	601 patients with active epilepsy seen in 1990 in specialist epilepsy clinics in National Hospital for Neurology and Neurosurgery (330 male, 271 female) age range 10-80 years (mean 32.5, 88% between 15 and 45).	Retrospective cohort study. Medical notes reviewed and information on deaths collected from GPs, hospital records, post-mortem reports, coroners' reports, and death certificates. Total 1,849 patient years follow up (to 30 June 1993)	24 patients died during the follow up period. SMR of 5.1 (3.3, 7.6). Mean age of death 35, range 18-73. Of the 24 deaths, 11 were sudden and unexpected.	Study not representative of all people with epilepsy, children not covered and older groups underrepresented with most being aged 15 and 45.

Authors	Year	Geographical area	Condition related to disability	Sample Size & characteristics	Study Design & Method	Results	Comment
Neligan, Bell, Johnson, Goodridge, Shorvon, & Sander	2011	UK	Epilepsy	1,012 people drawn from NGPSE (c.f. Cockerell et al 1994; Lhatoo et al 2001) from between 1984 and 2002. 564 had definite epilepsy, 228 possible epilepsy, and 220 febrile seizures.	Prospective cohort study flagged at the UK NHS Information Centre. Death certificates obtained for 298 individuals. Expected number of deaths estimated using death rates for England and Wales.	SMR for those with definite or possible epilepsy was 2.21 (95% CI 1.97–2.47), and was higher in those with definite epilepsy (2.55; CI 2.24, 2.91). SMRs by age group presented graphically only. Pneumonia (definite or possible epilepsy n=60 deaths, SMR 6.6 (5.1, 8.4) was a common cause of death.	This is a follow-up to Cockerell et al 1994 & Lhatoo et al 2001. There are no major differences from previous analyses but extra follow-up increases precision and narrows CIs.

Authors	Year	Geographical area	Condition related to disability	Sample Size & characteristics	Study Design & Method	Results	Comment
Paterson, Ogston, & Henry	1996	England and Wales	Osteogenesis imperfecta (brittle bone disease)	743 patients with osteogenesis imperfecta (383 type IA, 77 type IB, 123 type III, 90 type IVA, and 70 type IVB) were included. The total number of patient years was 6970.	Survey of patients in England and Wales (data sources unspecified). Observed mortality compared with that expected from the life tables for 1981 for England and Wales.	Total of 57 deaths. Osteogenesis imperfecta type IA mortality ratio 1.08 (0.64, 1.81). Composite group types IB, IVA & IVB mortality ratio 1.93 (1.17, 3.13). Type III life expectancy noted to be impaired but results in figure only (26 deaths in 123 people, 19 occurring before age 10).	Mortality in type IA no different to general population; for types IB, IVA & IVB life expectancy reduced to modest extent; type III life expectancy impaired.
Rani, Byrne, Cranswick, Murray & Wong	2011	UK	Children & adolescents prescribed antipsychotic medication	2,767 patients aged <18 years who had received at least one antipsychotic prescription	Retrospective cohort study. Data taken from GPRD for those receiving antipsychotic prescription from 1992-2005. Questionnaire to GPs for those who had died to obtain additional clinical information. Deaths due to pre-existing medical conditions excluded from analysis.	30 deaths, of which 24 excluded. For 6 deaths included, SMR 4.03 (1.48, 8.76). Causality assessments suggest only one case where death *possibly* associated with antipsychotics.	Elevated SMR may be due to underlying primary illness and/or inadequate management of underlying medical conditions (including epilepsy, depression).

Authors	Year	Geographical area	Condition related to disability	Sample Size & characteristics	Study Design & Method	Results	Comment
Schoemaker, Swerdlow, Higgins, Wright & Jacobs	2008	UK	Turner syndrome	3,439 women diagnosed between 1959-2002 were followed to the end of 2006, DOBS from <1950 to 2001.	Retrospective cohort study. Data drawn from 27 of 29 Cytogenetic centres in UK. Patients flagged with NHS Central Register. Cause of death coded from ICD9.	296 deaths occurred. SMR 3.0 (2.7, 3.4). Age specific all cause SMRs <15 = 4.9 (3.2, 7.2); 15-44 = 3.9 (3.1,4.8); 45-84 = 2.6 (2.2, 3.0). Cause specific SMRs given.	Mortality threefold higher in Turner syndrome than in general population.
Swerdlow, Higgins, Schoemaker, Wright & Jacobs	2005	Britain	Klinefelter syndrome	3,518 men diagnosed since 1959, followed to mid-2003	Retrospective cohort study. Data obtained about patients diagnosed with Klinefelter syndrome at almost all cytogenetics centers in Britain, as far back as records were available.	461 deaths. SMR 1.5 (1.4, 1.7). Cause specific SMRs also reported. Mortality was particularly raised for some specific causes of death.	Authors note that less than a third of cases of Klinefelter syndrome come to clinical diagnosis & cases that come to diagnosis may be different to those that do not.
Thomas, Symmons, Brewster, Black & MacFarlane	2003	Scotland	Juvenile chronic arthritis (JCA)	499 males & 747 females with JCA identified from Scottish inpatient records 1981 to 2000	Retrospective cohort study of inpatients with recorded diagnosis of JCA. Computer linkage to national register of deaths with mortality follow-up to end 2000.	17 deaths for males, SMR 3.39 (1.97, 5.46); 22 deaths for females, SMR 5.09 (3.19, 7.75)	Increased risk of mortality. Results may not generalize to patients treated in primary care. As number of deaths small, CIs for SMRs very wide.

Authors	Year	Geographical area	Condition related to disability	Sample Size & characteristics	Study Design & Method	Results	Comment
Tyrer & McGorther	2009	Leicester city, Leicestershire & Rutland	Moderate to profound ID	2,995 adults with moderate to profound ID who were on the Leicester LD register. Identified deaths in those aged 20 or over between January 1993 and December 2006	Retrospective cohort study. Cause of death identified using information from death certificates at the Office of National Statistics (ONS). SMRs were calculated for each underlying cause of death	503 (17%) died during the 14 year study period (30, 144 person years). Overall, mortality was almost three times as high compared to the general population (SMR 2.77 (2.53, 3.03)).Cause specific SMRs also given.	Mortality from a substantial number of causes is greater in people with ID than in the general population, including potentially preventable causes such as respiratory infections, circulatory system diseases and accidental deaths.

Authors	Year	Geographical area	Condition related to disability	Sample Size & characteristics	Study Design & Method	Results	Comment
Tyrer, Smith & McGrother	2007	Leicestershire & Rutland including Leicester City	Moderate to profound ID	2,436 adults with moderate, severe or profound ID on Leicestershire Learning Disability Register; 19% Down's syndrome. Mild ID excluded.	Retrospective cohort study. Those on register who had died identified using mortality data from ONS. Ascertained all cause mortality by age and gender for those aged over 20 years on register between 1993 & 2005.	409 (17%) died during the study period. SMRs given in 10 year age bands were: all ages = 3.24 (2.93-3.56); age 20-29 = 11.50 (8.14-15.78); 30-39 = 8.45 (6.19-11.27); 40-49 = 4.68 (3.41-6.26); 50-59 = 5.59 (4.52-6.83); 60-69 = 3.45 (2.75-4.26); 70+ = 1.51 (1.23-1.83). SMR for those with Down syndrome was 7.60 compared to 2.70 for those without.	Overall, mortality was over three time higher in the ID population than in the general population but varied considerably with age. Adults in older age groups had mortality rates more similar to the general population suggesting a healthy survivor effect. Mild ID excluded from study.

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