The future need for social care services for adults with disabilities in England 2012–30

KEY POINTS FROM THE RESEARCH

- All the scenarios included in the modelling suggested sustained growth in the need for social care services for adults with physical or learning disabilities over the time period 2012–30.
- For younger adults with physical disabilities, compound annual growth rates in the number of users of adult social care vary from 1.8% to 6.5% depending on assumptions. These projections would involve providing support to between an additional 6,000 to 46,000 young adults with physical disabilities over the next ten years.
- 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 deeming some current users as ineligible for social care services 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 in the number of users of adult social care vary from 2.0% to 2.7% depending on assumptions. These estimates would involve providing support to between an additional 37,000 to 52,000 adults with learning disabilities over the next ten years.
- A 'no growth' scenario in the number of users of adult social care

The project's aim was to estimate changes in the need for social care services for adults with disabilities in England between 2012 and 2030.

The team collected information on the assessed level of eligibility for samples of children aged 14–16 identified as having special educational needs (SEN) and explored the relationship between SEN and disability. The project used the new field-generated estimates of eligibility to: (1) update the team's previous estimates of future need for adult social care services for people with learning disabilities; and (2) extended this work to estimate future need for adult social care services for people with physical disabilities (including sensory impairment) in the age range 19–30.

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services for people with learning disabilities could only be achieved by either deeming some current users as ineligible for social care services or by rationing access to services to young people with learning disabilities with 'critical' need and 25% of those with substantial need.

A number of factors that would have an impact on future need could not be taken into account in the modelling. These included: effects due to international migration; changes in the incidence of disability over time; and changes in mortality rates among people with disabilities over time.

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NHS
National Institute for
Health Research

BACKGROUND

The project builds upon and extends the team's previous work on estimating future need for social care services among adults with learning disabilities. ^{1,2} The most recent update of that work had suggested a sustained growth over the time period 2011–30, with estimated average annual increases in the number of service users in this group varying from 1.2% to 5.1% depending on assumptions (average 3.2%).

The most critical source of uncertainty in the previous model was in the validity of the 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 learning disabilities. Those estimates had been developed through consultation with relevant stakeholders (primarily disabled people's organisations and field agencies). One of the key aims of the new project was to test out and refine these assumptions through field-based research.

FIELD-BASED RESEARCH

The proposed primary research involved attempting to collect information on assessed level of eligibility for samples of 50 children aged 14–16 identified as having special educational needs (SEN) in ten councils with adult social services responsibilities (CASSRs). Unfortunately, the fieldwork took place during 2010/11, a period of turmoil within CASSRs in England. Despite extending the period of data collection, the project was only able to collect data on 223 young people (45% of the target sample).

Given these difficulties, the team also carried out exploratory analyses of the association between SEN and the experimental disability statistics collected by the Department for Education (DfE) in spring 2011. These analyses suggested the DfE data were subject to a number of serious biases associated with social exclusion and socio-economic position that made their use untenable in this project.

The project was, however, able to use the new field-generated estimates of eligibility to update the previous findings on people with learning disabilities, and extend the analysis to people with physical disabilities (including sensory impairment) in the age range 19–30.

Table 1: Assumptions and data sources

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

Table 1 lists the key assumptions and data sources used in this project and indicates the degree of confidence in these assumptions/ data and an estimate of the sensitivity of the predictions to any reasonably expected error.

Estimating future need

The process of estimating future need for social care for a given group of disabled adults involved the following stages:

- Ascertaining the number of children in England with SEN associated with the adult disability category in question from the latest available DfE School Census;
- 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 become age 18 between 2012 and 2030;

- Applying estimates of the percentage of these children that are likely to become eligible for adult social care services under differing eligibility criteria;
- Using NHS Information Centre for Health and Social Care information to estimate the number and age profile of disabled adults using social care services in 2011/12;
- Adjusting the population of current adult service users for the expected effects of mortality over the period 2012–30;
- Combining these estimates with estimated inflows from child services to estimate net changes in need over the period 2012–30.

Three modelling scenarios were used for the rationing of adult social care:

- Scenario 1: Adult social care services would only be available to people with critical or substantial need.
- Scenario 2: Adult social care services would only be available to people with critical or substantial need and 50% of people with moderate need.
- Scenario 3: Adult social care services would only be available to people with critical, substantial or moderate need.

PEOPLE WITH PHYSICAL DISABILITY

Projections of future need

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.

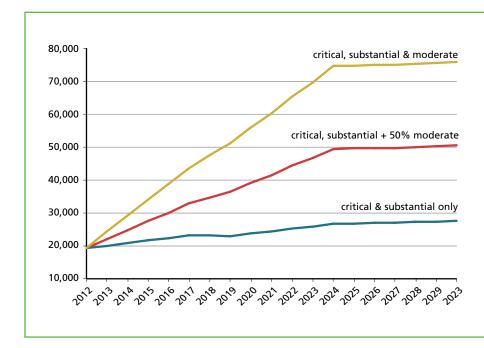
Figure 1 shows the estimates of need based on the results of the three modelling scenarios.

Characteristics of service users

The characteristics of young people with physical disability entering adult social care depend on the assumptions used in the estimates.

If services are provided to new entrants with critical or substantial need and 50% of potential new entrants with moderate need (scenario 2), the model shows that just over one in five new entrants between 2012 and 2024 will be from a British minority ethnic community and around one in four from a poor household or deprived community. Just over 87% of new entrants have a physical disability, and the remainder have single or multiple sensory impairments.



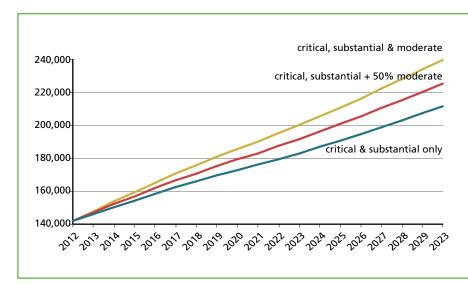


All three scenarios suggest sustained growth in the need for social care services for younger adults with physical disabilities over the period 2012–30.

Compound annual growth rates vary from 1.8% (scenario 1), to 4.7% (scenario 2), to 6.5% (scenario 3).

For all estimates the annual percentage growth rate slows from 2013 to 2022 and then stabilises, reflecting changes in birth rates over the last two decades.

Figure 2: Estimated number of users of adult social care with learning disability 2012–30



All three scenarios suggest sustained growth in the need for social care services for adults with learning disability over the period 2012–30.

Compound annual growth rates vary from 2.0% (scenario 1), to 2.4% (scenario 2), to 2.7% (scenario 3).

PEOPLE WITH LEARNING DISABILITY

Projections of future need

Figure 2 shows the estimates of need based on the results of the three modelling scenarios.

As in the team's 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.

Characteristics of service users

The characteristics depend on the assumptions used in the estimates. In scenario 2, the model estimates 25% of new entrants from 2012 to 2030 belong to British minority ethnic groups and over one-third will be from deprived households and/or deprived neighbourhoods. In terms of the severity of the learning disability, the split was mild/moderate (59%), severe (30%) and profound multiple (11%).

DISCUSSION

The findings suggested sustained growth in the need for social care services for adults with physical or learning disabilities over the time period 2012–30. However, there were a number of factors that would have an impact on future need that the modelling was not able to take into account. These included:

Effects due to international migration. The team believes 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. There are competing pressures, some of which are likely to lead to an increase (e.g. increases in maternal age, improved survival of 'at risk' infants) and some to a decrease (e.g. more prenatal screening for Down's syndrome, fewer 'at risk' infants developing disabilities). The team considered it unlikely that the net effect would have a significant impact.

Changes in mortality rates among people with disabilities over time. Current trends suggest mortality rates should continue to fall, but precise predictions are not possible. However, any error here would only lead to a marginal underestimate of future need.

Finally, it should be stressed that the estimates are based on 'need' rather than 'demand'. Changes in demand are likely to outstrip changes in need due to factors that will reduce the capacity of informal support networks (mostly unpaid female labour) to provide care. These factors include: more lone parent families; higher maternal employment; increases in the percentage of older people with learning disabilities; and changing expectations regarding the person's right to an independent life.

^{1.} Emerson E, Hatton C (2011) Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England: An Update. Stockton-on-Tees: Learning Disabilities Public Health Observatory, North East Public Health Observatory.

^{2.} Emerson E, Robertson J, Coles B, Hatton C (2012) Estimating the Need for Social Care Services for Adults with Disabilities in England 2012–2030. Lancaster: CeDR.