

Younger disabled adults

Outline of a research project
funded by the NIHR School
for Social Care Research

What will be the future demand at a local level for social care for younger disabled adults?

It is impossible for local authorities to plan social care services unless they know how many people will need support in future. At present, few Councils with Adult Social Services Responsibilities (CASSRs) have access to such information in relation to the current and future local need for social care support for younger disabled adults. This creates challenges for effective service commissioning and undermines strategic decision-making relating to the best use of resources.


Advances in care mean that many young people with complex disabilities survive well into adulthood, with the result that the number and characteristics of adults with social care needs is changing rapidly. Currently there is no single source of projected local need that covers all categories of younger disabled adults, for instance including those without Special Educational Needs (SEN) but with long-term degenerative illnesses or who are dependent on medical technology. It would therefore be of benefit for individual local authorities to have access to comprehensive projections of local need.

This project

- will develop a web-based modelling tool that local authorities (and others) can use to predict future need for social care services for all younger disabled adults over the next ten years.

It aims to

- extend an existing model that projects local service needs of people with learning disabilities so that the projections cover all young disabled adults
- produce more accurate estimates of how many children with particular categories of SEN will need support
- establish an evidence base for these projections through field work with children with SEN, focusing on the transition planning by the local social services department, the likely future eligibility for adult social care, and the types of support that will be required
- publish an open access web-based version of the predictor model that will enable local councils to obtain projections of the future need in their area for social care services for all younger disabled adults.



Improving the evidence base for
adult social care practice

Research project outline

WHAT IS THE CONTEXT?

Effective commissioning of adult social services requires that commissioners have access to credible information on the local need for care, and how the level of demand may vary in the short to medium term future. In a budget-constrained environment, such projections are important for making strategic decisions relating to the best use of resources.

At present, however, few Councils with Adult Social Services Responsibilities (CASSRs) have access to projections of the current and future local need for social care support across all younger disabled adults. The urgency for better information to support the planning of social (and health) care has repeatedly been made.

There is already evidence that overall demand is likely to rise substantially. Previous work by members of the project team has produced estimates of the changing need for social care services specifically for adults with learning disabilities in England from 2009 to 2026. The results suggested sustained growth in demand given current policy objectives; projected average annual growth in need over the period varied from 3.20 per cent (the lower estimate, with services provided to 50 per cent of new entrants with moderate needs) to 7.94 per cent (the upper estimate, with services to all new entrants with moderate needs). These estimates would mean providing support over the next ten years to between an additional 47,000 (34 per cent, lower estimate) to 113,000 (82 per cent, higher estimate) adults with learning disabilities.

As mentioned, this earlier work only addressed the social care needs of adults with learning disabilities, whereas local councils would benefit from comprehensive projections covering the future needs of all young disabled adults.

Many young people with complex and multiple disabilities are surviving much longer into adulthood, thanks to medical advances. On the other hand, there are also factors that may serve to decrease the incidence/prevalence of disability (e.g. availability of pre-natal

screening and terminations, changes in maternal age at birth, different patterns of exposure to environmental toxins and teratogens).

Where robust information is available, it is possible to build these various changes in prevalence into a model to give commissioning bodies an understanding of the overall changing size and characteristics of the younger disabled adult population.

This type of information can also be combined with data on service provision in order to inform judgements regarding equity of access to, and the coverage of, existing provision. These issues are particularly relevant given the current emphasis on prevention across health and social care, as identification of inequalities enables preventative interventions.

Overall, this project will provide better information both for individual local councils and nationally.

HOW WILL THE PROJECT WORK?

This project will build on methods previously developed for estimating changes in need for local areas. That approach used data about current users of adult social care services, together with information about possible new entrants into adult social care services. This study's analysis similarly uses information about the cohort of disabled 14 to 16 year-olds who will make the transition to adult social care in the next few years.

The most comprehensive, routine local data on child disability is in the School Census. This data, which is collected every school term, covers all school pupils (including those with severe and complex needs in residential schools) and provides information on any child's Special Educational Needs (SEN). It also collects key demographic information (age, gender, ethnicity, socioeconomic circumstances).

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The earlier model combined School Census data, administrative information on adult service provision, and disability-specific child and adult mortality data in order to project local and national changes in need for adult social care support for people with learning disabilities. This new project will extend coverage beyond individuals with learning disabilities to cover all young disabled adults.

STAGE 1: Extending the model

Extending the model's coverage will require robust estimates of:

- age-specific mortality rates for children and younger adults with physical or sensory impairments, health conditions associated with a high risk of disability and mental health problems
- changes over time in the incidence and prevalence of disability
- the extent to which children may be considered disabled by local councils and have significant care needs, but not be included in SEN classifications.

These estimates will be derived from a systematic review of the relevant literature combined, where appropriate, with consultation with field agencies and other relevant stakeholders.

STAGE 2: Field work

Primary research will be carried out in a sample of ten local authorities in England in order to develop more accurate estimates of need in relation to specific categories of SEN. The model requires that estimates (upper, middle, lower) are made for the percentage of children with a specific SEN (e.g., profound multiple learning difficulties, multiple sensory impairment, specific learning difficulties) who will meet various eligibility criteria for adult social care on transition to adulthood. The estimates used in the earlier model were derived through consultation with disabled people's organisations and field agencies and would be strengthened by testing against data from transition planning.

The ten authorities will be randomly selected from CASSRs with populations greater than 100,000 in the North West, North East, and Yorkshire & Humber regions, across the spectrum of social deprivation. In each selected local authority, information will be collected from case records on a random sample of 50 children aged 14–16 who are identified in the School Census as having SEN.

The final sample of 500 children will include children with autistic spectrum disorder, behavioural emotional and social disorder, moderate learning difficulties, physical disabilities, speech language and communication needs, severe learning difficulties, specific learning difficulties, hearing impairment, profound multiple learning difficulties, visual impairment and multiple sensory impairment.

For each child the project will collect information on:

- what planning has been undertaken for their transition to adult services
- how likely they are to need adult social care services when they become adults
- what specific types of social care they will need in the next five years.

This data will be linked to key demographic information in the School Census. The results of the fieldwork will generate proportional 'need estimates' for each category of SEN, and how these may change over time. These will then be applied to the population of children with SEN who are entering adulthood.

Project publications

The project's main output will be the open access web-based predictor model. The project team will also provide a short administrative report, one peer-reviewed paper, a short note reflecting on the methods used and any issues/lessons that arise, and a 'Findings' document to be placed on the SSCR website. The project results (and information on the availability of the predictor model) will be published on the Centre for Disability Research website and publicised widely.

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HOW DOES THE PROJECT FIT THE AIMS OF THE SCHOOL FOR SOCIAL CARE RESEARCH?

This project will provide a new open access predictor tool which will enable national and local government more accurately and efficiently to plan and commission services across the whole spectrum of disabled younger adults. This will improve the deployment of public resources and contribute to achieving optimum social care outcomes. Indeed, in recent years, commissioners have persistently called for better information to support the planning of social care given the changing population characteristics of younger disabled adults.

By providing a robust basis for estimating current and future need, the project will also improve the ability of councils to make judgements on equity of access to, and the coverage of, the existing provision of social care services. Tackling such inequalities in health and social care is a key aspect of preventing, reducing or delaying, the need for more intensive services in the future. Identifying unmet need is also an important step towards empowering and safeguarding young disabled adults who are not receiving the services they require.

The NIHR School for Social Care Research

The School for Social Care Research was set up by the National Institute for Health Research to develop and improve the evidence base for adult social care practice in England. It officially launched on 1 May 2009 with funding of £15 million over five years.

The School conducts and commissions high-quality research across five overlapping programme areas:

Prevention and reduction – How can we best prevent or reduce the development or exacerbation of the circumstances that lead to the need for social care?

Empowerment and safeguarding – How can we best empower and safeguard people who use social care services?

Care and work – How can we best equip and support people – practitioners, volunteers, informal carers – to provide optimum social care? How can we ensure that people who use social care and their carers are enabled and supported in paid work and other types of meaningful activity?

Service interventions, commissioning and change – What interventions, commissioning and delivery arrangements best achieve social care outcomes?

Resources and interfaces – How can social care and other public resources best be deployed and combined to achieve social care outcomes?

Further information about the NIHR School for Social Care Research is available at www.sscr.nihr.ac.uk

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Contact:
Professor Eric Emerson
Centre for Disability Research
Division of Health Research
Lancaster University
Lancaster
LA1 4YT

Telephone:
07730 539 060

Email:
eric.emerson@lancaster.ac.uk

