

Complex and severe needs

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

How should care and support be provided to people with complex and severe needs?

The number of people with complex and severe needs is growing as a result of advances in medical science and an ageing population. The multiple needs of individuals can include learning difficulties, physical disabilities and mental health disorders.

This poses significant challenges to adult social care commissioners and providers. A personalised and specialised support package that addresses a breadth of different, but inter-related, needs is expensive. It also requires coordination across a wide range of services, professionals and other workers, particularly across health and social care.

To encourage the delivery of appropriate services, a better understanding is needed of the effectiveness of current arrangements, the potential for improvement, and what might constitute 'best practice'.

This project

- is a scoping study of existing practice and innovations in commissioning and delivering care and support for people with complex and severe needs.

It aims to

- identify the key features of service and support arrangements that are valued by disabled people with severe and complex needs and their carers
- identify examples of service initiatives that have been demonstrated through research evidence to be effective or successful and which could therefore constitute 'good practice'
- examine current service patterns and practice, and assess how far they are consistent with 'good practice' as defined by users and/or research evidence
- recommend appropriate service developments in adult social care and related services.



Improving the evidence base for
adult social care practice

Research project outline

WHAT IS THE CONTEXT?

Adult social care services are facing significant new challenges due to the changing population of disabled and older service users:

- Advances in medicine and surgery mean that children born very prematurely or with severe disabilities can now survive into adulthood, albeit with a combination of learning disabilities and sensory, physical and behavioural problems.
- Adults suffering major accidents or life-threatening illnesses are also more likely to live, despite severe impairments.
- At the same time, an ageing population will mean increasing numbers of older and very old people experiencing from dementia alongside physical health problems.

On average, 630 young people with profound learning disabilities will enter adult social care each year for the next 10 years.

The number of older people with complex needs is projected to increase from 551,000 to 631,000 in the decade to 2012.

These individuals present a breadth of different, but inter-related, needs that require substantial coordinated support from a wide range of services, professionals and other workers, particularly across health and social care. The demands on informal carers are also likely to be very extensive.

Delivering an optimum support package for someone with complex and severe needs is both expensive and organisationally demanding.

Service Commissioning

- Local specialist services are not always available.
- Flexibility is needed in the use of budgets across sectors and agencies.
- Local joint strategic needs assessments by local authorities and primary care trusts have been weak for some groups of disabled people with severe and complex needs.
- Comprehensive support may also involve agencies such as Learning and Skills Councils, the Independent Living Fund, and Department for Work and Pensions employment services.

Operational issues

- Users still face multiple assessment procedures as there has been only limited progress in aligning and integrating assessments and eligibility criteria across different services and sectors.

Front-line delivery

- Service provision across social care and health is still often fragmented and poorly coordinated.
- Direct payments and personal budgets have the potential to bridge the gap between social care and health aspects of personal care, but implementation processes are often inappropriate for people with the most complex and expensive needs.
- Despite recognition of the benefits among severely disabled children, the 'key worker' model – which assigns responsibility for coordinating services from different agencies to a single professional – has not been widely adopted for adults with severe and complex needs.

Research project outline

HOW WILL THE PROJECT WORK?

The project will focus on the needs of three groups for whom services appear particularly under-developed:

- young adults with complex health problems or life-limiting conditions
- adults surviving major accidents with traumatic brain injuries and/or physical impairments
- older people with dementia and additional physical or sensory impairments.

The research will investigate existing evidence of good practice from users and independent research, and identify models that would benefit from further evaluation. It will be carried out in three stages.

STAGE 1: Consultation with key stakeholders

Identifying arrangements that are valued by users, carers and other stakeholders.

- Telephone interviews will be held with stakeholders from specialist voluntary organisations and relevant professional and service organisations that work with, and represent, the target user populations.
- Discussions will be held with service users and carers, either individually or in groups depending on their specific needs.
- Questions will cover the actual and potential role of social care services in delivering coordinated support; users' priorities for developing good quality services; and the extent to which users and/or families are involved in developing service arrangements.

STAGE 2: Literature review

Identifying arrangements that have been demonstrated through research evidence to be effective or successful.

- The review will establish the size and robustness of the evidence about

arrangements for commissioning, organising and delivering services for people with severe and complex disabilities, particularly the three groups that are the focus of the study.

- Particular focus will be on whether, and how, service arrangements have been evaluated and whether the criteria for success match those identified in the consultation with stakeholders.
- The review will cover research published in English since 2000.

STAGE 3: Case study examples of good practice

Data generated in stages 1 and 2 will be used to identify up to six case study sites, where arrangements for commissioning, organising and/or delivering services for people with complex needs will be investigated in detail.

Semi-structured interviews will be conducted with the key staff involved in each of the case study examples to generate descriptive accounts of the establishment, operation and any known outcomes of the example/initiative.

Interviews will be conducted with staff from different sectors/organisations and at different levels within these organisations to reflect different perspectives and enable accounts to be triangulated. These detailed descriptions will provide an invaluable starting point for the future evaluation of service models.

Project publications

A final report will be published on completion of the project, accompanied by an Executive Summary which will be widely distributed. Further dissemination will be through academic journal articles and the specialist press.

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

This project will improve the evidence base across a number of the School's programme areas. Reliable information is needed on the service features that are valued by individuals with complex and severe needs so that these individuals can be empowered as users and their preferences respected. Without this information it is unlikely that commissioners and managers can understand what social care interventions – in combination with other services – are likely to achieve the best outcomes.

The project aims to demonstrate what interventions, commissioning and delivery arrangements achieve the optimum social care outcomes for the three target groups. As well as assessing current practice against evaluated research evidence base, the study may identify service models that have the potential to be transferable to other groups of service users, and new models that would benefit from further evaluation.

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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Care and Support for People with Complex and Severe Needs: Innovations and Practice. A Scoping Study

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