

Skilled support for people with complex needs

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



Improving the evidence base for
adult social care practice

What impact does skilled social care support have on costs and the quality of life outcomes of people with learning disabilities and complex needs?

Social care services provide support to many people with learning disabilities and complex needs who would formerly have lived in NHS long-stay institutions. However, care services often have difficulty meeting the wide-ranging needs of these people. The opportunities presented by more personalised service models require the support of skilled staff if they are to be realised by people with complex needs. The quality of staff support has been shown to be a critical factor in determining a person's quality of life in small group homes and supported accommodation.

In this context, firmer evidence is needed of the effects of skilled support on a range of user outcomes and on the costs of service provision. This will enable people with learning disabilities (and their advocates), service providers and commissioners to identify and promote the most appropriate skilled support and to achieve value for money in the provision of services.

This project

- will evaluate the impact of skilled staff support on the lives of people with learning disabilities and complex needs, and describe the nature of the support required and the implications of providing this support.

It aims to

- investigate whether skilled staff support, as defined by previous research, is associated with higher quality of life for people with complex needs
- explore which domains of quality of life, if any, are influenced by skilled staff support
- establish whether, having controlled for needs and characteristics of participants, better outcomes cost more money
- consider how aspects of organisation and management relate to the provision of skilled staff support
- draw conclusions about the implications, for service organisation and management, of providing skilled support.

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WHAT IS THE CONTEXT?

The replacement of long-stay NHS institutions with small group homes, supported living and services in the community has brought many benefits for people with learning disabilities. These include stronger civil rights, better material and social conditions, and more choice and control over their lives. Research has shown that these improvements all contribute to an individual leading a fuller life and reporting higher satisfaction levels.

Not surprisingly, however, it is more challenging for social care services to provide the optimal support necessary for individuals with more severe disabilities. In particular, key groups of disabled people with complex need often experience less good outcomes, for instance people with severe and profound intellectual disabilities whose behaviour presents a challenge, or who have multiple disabilities, or who have autistic spectrum disorder.

Such individuals are often unable to make full use of the opportunities presented by new service models because they depend on skilled support from staff to do so – and that skilled support may not always be forthcoming.

There are several ways in which staff can play a central role in mediating access to, and use of, opportunities available to people with complex needs. Staff may control access to materials and activities. Their skills in using alternative forms of communication are likely to enhance, or diminish, the ability of someone with complex needs to exercise choice and take control over the course of their lives. Similarly, the level of assistance and facilitation provided by care staff makes it more, or less, likely that individuals will experience the full rewards of taking part in a task or activity.

It is often the quality of the social interaction between staff and the people they support that either reinforces a pattern of engagement in meaningful activity – or results in passivity and inactivity. Care workers are likely to shape a person's behaviour by the feedback and reinforcement they provide.

Codifying beneficial care practices

Various frameworks have been proposed to codify and describe beneficial care practices such as, for example:

- active support
- augmentative and alternative communication
- positive behaviour support
- the National Autistic Society 'SPELL' framework.

These approaches are becoming more widespread but evaluation is patchy and has focused on a limited range of outcomes.

Thus the opportunities presented by more personalised service models require appropriate staff skills if people with complex needs are to make the most of their life experiences.

Improved evidence of the impact of skilled support is therefore important to enable people using services and their advocates to identify staff practices associated with good outcomes and to specify these in their care packages. A better understanding will also enable people providing services to recruit, train and manage staff in order to promote these care practices, and to assist people commissioning, planning or regulating services to achieve better value for money by requiring effective staff practices.

HOW WILL THE PROJECT WORK?

This research will provide evidence of the effects of skilled staff support on a comprehensive range of outcomes and on costs for three important sub-groups of people with complex needs. The study has three stages:

STAGE 1: Initial set-up

In seeking participants for the project, the research team will identify adults living in

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supported accommodation – small group homes, supported living or self-directed services – who have severe and profound learning disabilities as well as:

- serious challenging behaviour, and/or
- additional multiple disabilities, and/or
- autistic spectrum disorders.

The project will recruit approximately 65 people for each of these three sub-groups, split evenly between those receiving skilled staff support (the experimental group) and those receiving broadly comparable services not including skilled support (the comparison group).

STAGE 2: Fieldwork

Measurement will cover eight domains of quality of life: social inclusion, physical well-being, interpersonal relations, material well-being, emotional well-being, personal development, self-determination and rights. In addition, data will be collected on aspects of service organisation, care practices and costs.

Information gathering will make use of questionnaires, direct observation and interviews.

Some of the questionnaires will be sent to the participant's service provider for completion ahead of the researcher's observational visit. During the visit itself, the researcher will observe each person in turn during a two hour period. A separate interview will take place with the service manager about the support provided and the way the service works.

STAGE 3: Analysis of data

Three types of analysis of the quantitative data will be carried out:

- Descriptive analysis of the needs and characteristics of people supported, their quality of life across all the domains, the quality of staff support, and the characteristics of the service and costs.

Service utilisation rates for the whole sample and by group will be described, and the study will explore the extent to which the various service agencies (community health or social care, for example) bear the costs of supporting adults with complex needs under different living and support circumstances.

- Groups of participants from the experimental and comparison groups will be matched for needs and characteristics. Comparisons will then be made to explore the differences in outcomes and costs between people receiving skilled staff support and those receiving other support.
- A series of multivariate analyses will be carried out to illustrate relationships between process and outcome variables. This work will cover the relationships between support, quality of life, participant characteristics, staffing characteristics and costs.

The project will also produce a qualitative description of the support provided. This will illustrate issues not apparent in the quantitative measures and support comment on the implications of the project results for issues such as management, training and commissioning of services.

Project publications

The principal product of the research will be one or more papers in refereed journals. Results of the project will also be presented at national and international conferences, and incorporated in the academic teaching and training provided by the University of Kent's Tizard Centre.

A 'Research Findings' will be published on the Centre's website, and summary articles published in the Tizard Learning Disability Review and submitted to professional social care journals. Project results will be incorporated in presentations to professional audiences where appropriate.

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

Skilled support from care staff is key to empowering and safeguarding individuals with learning difficulties and complex needs.

However, further research is needed to understand what forms of skilled support are most effective at best achieving social care outcomes. Once that is better understood, users and their advocates will be better placed to specify the role these elements should have in a care package. At the same time, care staff can be recruited, trained and managed to provide these care practices.

Public resources will also be deployed in a more cost-efficient manner if service commissioners, planners and regulators are aware of the most relevant care skills and can then ensure that effective skilled staff support is a required provision.

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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Costs and outcomes of skilled support for adults with complex needs in supported accommodation

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