

Choice and control for physically disabled young adults

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



Improving the evidence base for
adult social care practice

Taking On and Taking Over: physically disabled young adults and their care and support arrangements

Central to the policy of personalisation is the need to provide opportunities and support for service users to achieve their preferred level of choice and control over their care arrangements. This is particularly important for young people as they transfer to adult services, move towards adulthood and seek increasing independence. Yet little is known about the experiences of young adults with physical disabilities and chronic or deteriorating health conditions (but without learning disabilities) as they enter adult social care. It is likely that many of these individuals may aspire independently to manage their own care and support arrangements, regardless of the complexity of their care packages.

This study aims to fill a gap in the existing evidence base by identifying what support this group of young adults needs from adult social care in order to achieve choice and control over their services. It also seeks to highlight what is currently working well or is inhibiting progress in this area.

This project

- will identify what additional support is needed for physically disabled young adults (and their families) to achieve their preferred level of choice and control over care and support arrangements.

It aims to

- investigate the factors which facilitate choice and control, and the barriers which inhibit this transition
- explore the current and potential roles of statutory and independent sector adult social care and planning/brokerage services in this area
- assess the roles of transition support services in preparing young people (and their families) to achieve their preferred levels of choice and control
- provide guidance for adult social care, including transition support services, and non-statutory services about what works and what more needs to be done to enable and support physically disabled young adults to implement choice and control.

Research project outline

WHAT IS THE CONTEXT?

The personalisation agenda in social care has prompted a multitude of studies on issues of choice and control for working age adults with social care support needs. To date, however, little research has been carried out on the experiences of young adults with physical disabilities or complex health conditions as they enter adult social care, and how best to support individuals to achieve their preferred level of choice and control over their care and support.

Young adults aged 18 to 25 with physical disabilities (but without learning disabilities) constitute a relatively small proportion of users of social care services. This group includes, for example, individuals with cerebral palsies, neuromuscular degenerative conditions and acquired impairments (e.g. from road traffic accidents). The absence of cognitive impairment means that assuming responsibility for overseeing their support arrangements is often a realistic aspiration, yet relatively little is known about how best to effect this transition to personal choice and control.

Young adults with physical disabilities face a particular set of challenges on transition to adult services (see box). Achieving their preferred level of control can impose significant demands and, given their relative naivety and lack of experience, may not be sustainable or always result in positive outcomes. There are examples of young adults living independently whose basic care needs have gone unmet because they do not know how (or have the confidence) to voice their needs; others find that managing their care package is a full-time activity which can be demanding and stressful.

Adult social care practitioners have an important role to play in overcoming these difficulties and supporting individuals to make this transition. Help may also be needed for parents and carers, who must also make important adjustments.

This study aims to highlight the key issues faced by young adults, parents/carers and practitioners; and the implications for transition services and adult physical disability teams.

Challenges on transition

Young adults with physical disabilities face particular challenges in achieving choice and control after moving from child to adult services:

- Experiences of adult services will contrast significantly with the family-centred approaches of children's services and this may conflict with the way young adults still want their parents to be involved
- Young adults may have previously had little involvement in decision-making and management of their care packages. They may lack the skills needed to manage a budget, select services, and recruit and manage personal assistants
- Their impairments and health care needs may require complex packages of care and/or support from specialist providers
- Personal and intimate care provided by adult services may involve paid personal assistants in place of the parental care largely provided to children
- Their age and the complexity and chronic nature of need may not fit well with typical practices and approaches in adult physical disability teams, for whom they represent a minority group.

HOW WILL THE PROJECT WORK?

The research will be conducted in four local authorities with relatively high numbers of young people with physical disabilities entering adult social care, and evidence of good practice in transition support. It will seek to answer six main research questions through qualitative research methods including individual face-to-face interviews, telephone interviews and focus groups. These methods will be used to obtain the views and experiences of:

- Physically disabled young adults (18–25 years) who are starting to manage their social care support arrangements
- Parents (with the young adult's consent)
- Practitioners in adult physical disability

Research project outline

- Lead officers/managers in transition services and physical disability teams in adult social care
- Local and national specialist voluntary and private sector organisations.

In brief, the six key questions are:

- What are the young adults' aspirations for their level of choice and control over their care and support?
- What support do the young adults need to exercise their preferred level of (or, for them, optimum) choice and control?
- What factors – service/organisational, condition, individual and/or family-focused – facilitate or act as barriers?
- What is the perceived role of transition services in preparing these young adults (and their parents) to be able to exercise choice and control?
- How is responsibility shared between young adults and parents for managing the young adult's support arrangements and what role do adult social care services play in supporting each in their desired levels of responsibility?
- What roles do specialist voluntary and private sector support planning and brokerage organisations play in working with this group to facilitate the preferred level of choice and control?

STAGE 1: Data collection

Semi-structured interviews will be conducted with five to eight physically disabled adults from each of the four participating local authorities, with methods adapted to meet the communication needs and preferences of each individual. The discussions will include their aspirations for choice and control, experiences of working with local authority practitioners and other organisations and the perceived factors that promote or inhibit choice and control.

Interviews with parents will explore issues such as their role in the transition process, and what support they have received from services,

practitioners and specialist support planning and brokerage organisations.

Telephone interviews with senior managers will cover topics such as the authority's current approach and practice, the roles of transition services and adult physical disability teams, and details of other organisations that support the transition process. Interviews will also be carried out directly with a small number of third and/or private sector specialist support planning organisations to explore their role and services, including partnership working. Focus groups will be held in each authority with staff with relevant caseload experience to explore topics relating to the six questions.

STAGE 2: Analysis of data

Data analysis will be on-going throughout the study. Preliminary analysis of the young adults' and parents' interviews will identify and refine themes and issues which can then be explored in the subsequent interviews with managers, practitioners and specialist voluntary and private sector staff. The interview data will be processed thematically using Framework Analysis, which facilitates the exploration of similarities and differences in the views and perspectives of the different groups of participants.

STAGE 3: Feedback workshop

A workshop for practitioners and professionals who have participated in the study will be held towards the end of the project. Participants' feedback on the draft findings will be incorporated into the study's final reports and study outputs.

Project publications

An accessible 'Findings' summary will be sent to all English adult social care departments, transition teams, Think Local Act Personal, relevant specialist voluntary organisations and all study participants. At least one peer reviewed academic journal paper will be published, findings placed in a relevant 'trade press' outlet and a variety of dissemination events will be sought, including through the project's links with organisations such as the Muscular Dystrophy Campaign, Scope, and Preparing for Adulthood team.

Research project outline

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

This study will explore how disabled young adults entering adult services begin to take control of their own support arrangements, what factors facilitate this and what (if any) barriers they experience. It will also look at the views and experiences of parents/ carers in handing over the control that they previously exercised. The project thus directly addresses a key SSCR priority issue: how best can social care professionals empower users of social care services to exercise their preferred level of choice and control. The findings will fill a clear evidence gap as well as addressing key practice questions.

The study aims to identify the extent to which both transition services and adult social care practice currently support young adults to take control of their own arrangements. The project's analysis will help to equip social care services to provide the support that is most effective.

Using the results, the project's research team will be able to develop or fine-tune information or guidance specifically for this group and their carers. In highlighting the key issues faced by young adults, carers and practitioners, the research will help to shape and develop social care practice and suggest issues for further research or training.

The Research Team

The team brings together a number of experienced academics at the University of York's Social Policy Research Unit (SPRU).

Caroline Glendinning, Professor of Social Policy at SPRU, will oversee and supervise the project; ensure the research links with, but does not duplicate, other SPRU and SSCR projects; and contribute to the analysis and report writing.

Dr Wendy Mitchell, Research Fellow at SPRU, will take lead responsibility for running the project. She will design, conduct and analyse interviews; set up and run the advisory group; and contribute to analysis and writing.

Dr Nicola Moran and *Dr Jenni Brooks*, Research Fellows at SPRU, will design the topic guides for practitioner interviews; lead on conduct and analysis of interviews with transition and physical disability teams in adult services; interview parents and voluntary and private sector organisations that offer support planning and/or brokerage services; and contribute to analysis and writing.

Professor Bryony Beresford, one of SPRU's Research Directors, will supervise the fieldwork with young adults and parents and on transition issues; and contribute to analysis and report writing.

Project title:
Taking On and Taking Over:
physically disabled young
adults and their care and
support arrangements

Timescale:
1 July 2012 to
31 October 2013

Budget:
£202,110

Contact:
Professor Caroline
Glendinning,
Professor of Social Policy,
Social Policy Research Unit,
University of York,
Heslington,
York,
YO10 5DD

Telephone:
01904 321 950

Email:
caroline.glendinning@york.ac.
uk

