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Choice and change: disabled adults' and older people's experiences of making choices about services and support

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Extending choice to users of publicly-funded services is central to current policies. New opportunities for choice have been introduced in social care and personal budgets are being piloted for some health conditions. But how important is choice about services for disabled people and their families? This study investigated the realities of making choices about services and support over time, by disabled people of working age and older, who were likely to experience repeated choices due to their changing circumstances.

Key findings

- Having choice is important in improving health, maintaining independence and retaining chosen identities. However, exercising choice can be hampered by lack of information or acceptable options.
- Information is a precondition for choice; people are not always aware they have choices about services. People with gradually increasing support needs and no prior knowledge about services can be disadvantaged by their lack of access to relevant information at the pre-choice stage.
- The process of making choices creates some positive but mainly negative emotions. Negative emotions can lead to delays in making choices, thus also delaying any resulting benefits.
- People move in and out of using direct payments; sometimes an initial lack of support can result in people ceasing to use direct payments in favour of local council-commissioned services after relatively short periods. Direct payments users wanted more frequent contact with advisers; contact tended to reduce after initial reviews were completed.
- People revisit choices particularly after: changes in health or social circumstances; realising the outcomes of previous choices are not satisfactory; or interventions by professionals.
- People instigating revisions to choices of their own accord, and who have little contact with professionals, can lack support.
- People learn from both the processes and the outcomes of making choices. They share their learning with other people and learn from the experiences of others. However, opportunities for learning can be restricted for some people by the complexity of their conditions, or by limited life opportunities.

- Independence means different things to different people including being able to do things alone, make decisions, and be in control of one's life. However, the relationship between choice and independence is not simple; choices that sustain independence in one aspect of life can create dependency in other domains, or restrict the independence of other people.

Background

Extending choice to users of publicly-funded services is central to current policies. New opportunities for choice have been introduced in social care and personal budgets are being piloted for some health conditions. But how important is choice about services for disabled and older people and their families? Is choice empowering and important for wellbeing, or a challenge in the context of pain, poor health and uncertain prognosis? Most importantly, do choices lead to satisfactory and durable outcomes, given changes in health, support needs and wider circumstances?

This study investigated the realities of making choices about services and support over time with two samples of working age adults and older people. One group had fluctuating conditions (e.g. multiple sclerosis) that could require repeated choices and regular reappraisals of past choices. The other group had recently experienced the sudden onset of a disabling condition through accidents or trauma (e.g. stroke), which could involve major choices in the absence of previous relevant experience.

Findings

People discussed a range of choices, predominantly around health and social care, but also housing, employment and education; and, to a lesser extent, choices about respite care and accessible transport. Some were standalone choices; other choices formed parts of lengthy or complex chains of events, or had implications for choices in different areas of life.

Importance of choice

Having choice was felt to be important because it helped improve health, maintain independence and retain chosen identities. However, exercising choice was meaningful only if available options met individual preferences and people had access to relevant information; accepting the 'least bad' option did not feel like a 'real' choice. In practice, most participants thought their desired options were either limited or not available.

The choices participants made and the way they prioritised having choice in different areas of their lives varied according to age, the nature and severity of their condition, previous experiences of services, personal preferences, future expectations, and family circumstances. Participants with long-standing fluctuating conditions who had repeated contact with services were particularly likely to value opportunities for choice in relation to their healthcare. Choice of hospital was important to many participants; others prioritised receiving treatment at home or using complementary therapies instead of conventional medication. Older people and participants with fluctuating conditions prioritised choices over their future housing needs in anticipation of reduced independence.

Use of information

People used written, verbal and experiential information. Usually, participants used more than one source; they did not rely habitually on the same sources, even where these were particularly trusted. Healthcare professionals were trusted as sources of information more than social care or housing professionals. Lower levels of trust arose where participants perceived some professionals lacked knowledge or provided inconsistent information; this was the case particularly for information about direct payments. Timely access to information was important, especially for people without the support of emergency or crisis management teams.

Information was also a precondition for choice; people first required information about service availability and the possibility of choices. People with the gradual onset of support needs and no prior knowledge about services could be disadvantaged by their lack of access to relevant information at this pre-choice stage.

> *... nobody actually said to me that, you know, you need to get in touch with the occupational therapist. I knew that just because of the work I was in, and I knew where I needed to ask, what I needed to ask.*
> (Woman with fluctuating condition)

The role of emotions

Emotions played a big role in the process of making choices. Most participants discussed negative emotions, such as fear, worry, stress, isolation and anger. To a lesser extent, participants reported positive emotions, for example, excitement or hope. Causes of negative emotions were: decreased physical or mental well-being; uncertainty about available options or potential outcomes; fear of losing control, or of regret about not identifying all possible options; and lack of support in making choices. Changes in circumstances that were outside people's control but necessitated quick responses were especially stressful, such as sudden changes in the availability of medication. The absence of deadlines for making choices also caused stress, in particular for people with progressive conditions where responsibility for the timing of choices fell on them. Negative emotions resulted in people delaying making choices, thus delaying any resulting benefits.

> *... sometimes the status quo, although it may not be ideal, it's a case of*
> *you know what you're living with, you know what you're dealing with ...*
> (Woman with fluctuating condition)

The long term use of direct payments

People's journeys in and out of using direct payments were influenced by the associated administration and the help available with this. An initial lack of support could result in people switching from direct payments to council-commissioned services after relatively short periods. Direct payment users wanted more frequent contact with advisers. Those who experienced short-term changes in circumstances were unsure how these affected spending; this uncertainty could lead to unspent funds. Temporary moves to different council areas were also problematic. Over time, direct payment users learnt about sources of help; they built confidence and skills that were transferable to other areas, and also began to advise people new to direct payments. Employing personal assistants (PAs) reduced physical and emotional pressures on families, but employing family members as PAs could make ending the employment relationship difficult. Relationships with personal assistants evolved along a continuum from formal employee relationships to those akin to being part of the family.

Changing circumstances and revisiting choices

For people with long-term conditions, making choices about services is a continuous cycle, involving changing circumstances and re-evaluations of the appropriateness of previous choices. People revisited choices after: changes in health or social circumstances; realising the outcomes of earlier choices were not satisfactory; and interventions by organisations or professionals. Timeframes between making a choice and revisiting it varied from a few weeks to a few years. Some changes, for example reductions in mobility, forced people into reconsidering earlier choices, whereas others, such as improvements in health, meant people opted voluntarily to reconsider them. Fatigue with constant change could put people off revising choices. Revising choices in response to changing circumstances was facilitated by determination, energy, support from professionals and family, and the ability to challenge bureaucracy and seek information. People could be vulnerable to a lack of support if they instigated revisions to choices of their own accord, or had little contact with statutory or other organisations.

Learning from experience

Over time, participants built up knowledge and experience. People with long-standing/ fluctuating conditions, in particular, felt they had become experts at making informed choices as they became more knowledgeable about: their condition; available options and how to weigh them up; and the need to be proactive in searching for information, pressing professionals for action and planning ahead. An acknowledged lack of expertise in relation to a specific choice meant greater willingness to defer to professional advice.

People learned from both the processes and the outcomes of previous choices, and from both positive and negative experiences. They transferred their learning to subsequent choices in new situations. They shared their learning with other people and learned from the experiences of others, through family relationships and membership of voluntary groups. However, people who had less access to information, were less articulate or assertive, and had more limited access to networks of support, could be disadvantaged in developing expertise.

Choice and independence

Independence meant different things to different people. Some described it as being able to do things on their own. Others felt it was about being able to make decisions and being in control of their lives; having self confidence; or a combination of these. Whatever people's perceptions of their own independence, most people associated the loss of their independence with being forced into making a particular choice because there were no realistic alternatives and/or support to make choices.

> *To me independence is what I want, is what happens ... [independence] is ... choice, independence is access ...*
> *if I can get into the supermarket then I can shop ... but if somebody takes my disabled parking space then*
> *they've taken my independence, because I no longer can exercise that choice.*
> (Woman with the sudden onset of a disabling condition)

People made choices about support arrangements that would minimise their dependence on other people, or help maintain independence for longer. However, the relationship between choice and independence was rarely simple. Sustaining independence in one aspect of life sometimes created dependency in other domains, or restricted the independence of other people. Sometimes making one choice prompted other, further choices to be made, before there was any effect on people's sense of independence. Some choices could have unexpected consequences later in life. Concerns about independence also affected the timing of choices; some participants delayed making choices in order to maximise their current levels of felt independence, for example choosing to delay taking an auto-immune drug because it caused drowsiness.

Implications for professionals

The study illustrates the complex nature of making choices about services and other support. The main implications for policy and practice relate to help from professionals and the provision of information.

- Availability of help and support from professionals is extremely important, not just in providing information but in supporting people through the whole process of choice-making. People who could benefit most from support from professionals include: those who are less articulate; who have limited support networks; who have little on-going contact with professionals (including self-funders and people attempting to remain independent by not accessing services); and people with little background knowledge about services.
- Up-to-date knowledge and good communication skills are essential for professionals. The fast-changing policy environment in social care in particular may have made it difficult for some professionals to keep their knowledge up-to-date. If people considering their options for social care support are to be helped to feel confident, professionals, particular those advising on direct payments and personal budgets, need to maintain their knowledge levels.
- Disabled people with long-standing conditions develop a wealth of expertise about services and associated choices over time. They draw on this expertise when making choices, and they also learn from the expertise that others have developed through their membership of support groups. In contrast, people who are new to living with impairments, who have no personal experiences to draw from, who have little contact with professionals and no prior knowledge of welfare services, are disadvantaged in accessing information and other support. This group could benefit from the cultivation of ‘expert peers’ and encouragement to share common experiences.
- Choices can have unexpected consequences for people’s own independence and that of their close family members. It will be important for practitioners to support people in thinking about longer term outcomes and to adopt a holistic, family approach in helping people to make choices.

Methods

Study participants were recruited from a wide range of health and social services and voluntary organisations. They came from a diverse range of backgrounds across England.

Thirty working age and older people with fluctuating conditions and 20 with the recent sudden onset of severe impairments were recruited to the study; around two-thirds remained in the study after three years.

Participants were interviewed on at least three occasions between 2007 and 2010. The interviews explored recent experiences of making choices about services including: the information and advice people sought; the options considered; the factors taken into account; and the outcomes of these choices over time. The interviews also examined the roles played by other people – family, friends and professionals – in the choices that were made. Where another person was reported as having played an important role in a particular choice, consent was sought to approach that person for interview as well. In total 15 ‘significant others’ were interviewed.

Data were analysed to identify common and contrasting patterns. Analysis addressed specific questions and drew wherever possible on data from all interview rounds to maximise the longitudinal dimension of the study.

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Further details about the study and a range of journal articles about the research can be found at:

http://php.york.ac.uk/inst/spru/research/summs/DHPpanel.php

A companion summary from the same study is: Mitchell, W., Maddison, J. and Beresford, B. (2011) Choice and change: how disabled young people with degenerative conditions and their parents make choices about care and services, *Research Works*, 2011-05, Social Policy Research Unit, University of York, York.

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