Choice, dementia and people with learning difficulties

Like the rest of the population, people with learning difficulties are living longer and are also increasingly joining the growing numbers of people who have dementia. This trend throws up a range of issues for policy-makers and practitioners. Little attention has been paid to how choice and empowerment, fundamental to the community care reforms, can be made meaningful for individuals with learning difficulties and dementia. This research examined how far 20 people with these dual impairments, living in a range of settings, were involved in making choices and decisions about their own lives, and identified what facilitated or hindered that process. The study found:

- Most people were able to express clear preferences - including individuals who did not use speech to communicate.

- There were wide variations in the opportunities available to people to make choices. Most had some degree of choice over everyday matters but these were often restricted, partial or contested choices. Few individuals had a choice about where they lived, what they did during the day or who supported them. Hardly anyone had a say in planning their future.

- The attitudes and behaviour of staff and families influenced individuals' opportunity for making choices. Perceptions ranged from a conviction that people had the right and ability to make their own choices, and should be supported in doing so, to the view that people were unable to make choices at all.

The researchers conclude that:

- Staff and families have a key role to play in ‘preserving’ and maximising the involvement of people with dual impairments in decisions about everyday matters and future planning.
- People with learning difficulties, families and staff need clear and accessible information about living with dementia.
- Facilitating choice-making need not be difficult, although there may be some complex issues to work through. There is a need for more time, resources and appropriate training to support staff and family in promoting people's choice-making.
Introduction
The increasing longevity of people with learning difficulties raises a number of questions for service providers. This is particularly pertinent for people with Down’s Syndrome who have a high risk of both developing Alzheimer’s disease and of developing it at an earlier age than other people. The question of how best to develop and deliver services to meet the needs of people with learning difficulties and dementia is a key issue for planners and practitioners.

This project aimed to build upon current work on the exercise of choice by people with learning difficulties and on hearing the voice of people with dementia. The aim was to find out how far people with both learning difficulties and dementia are involved in making choices about their own lives and to identify what helps or hinders the process.

Opportunities to make choices
There were wide variations in the opportunities available to participants to make choices and in the importance given to this aspect of people’s lives by those around them. The overall picture, however, was that most people had little or no choice about where they lived, what they did during the day nor who supported them. Very few were given opportunities to make decisions about their future. Most people had some degree of choice about everyday matters such as what clothes to wear and what food to eat, although this also varied. There were some impressive examples of professionals facilitating choice, although these tended to be limited to a small number of settings. Choices about everyday matters were generally subject to some form of limitation imposed by others, usually care staff.

Only one person had control over her own finances and could choose how to spend her money. With respect to meals, while some people could choose what to eat, they were often restricted in some other aspect such as when to eat. Some participants did not even have the opportunity to decide what they wanted to eat. Choices were limited in other aspects of day-to-day living such as what time to get up or go to bed or when to do household tasks. However, it is important to note that these ‘regimes’ were not targeted specifically at people with learning difficulties who had dementia. (In fact, most of the findings from this research are generally relevant to difficulties and on hearing the voice of people with dementia. The aim was to find out how far people with both learning difficulties and dementia are involved in making choices about their own lives and to identify what helps or hinders the process.

Barriers to choice
The views of other people (e.g. family members, carers, practitioners) about participants’ choice-making abilities were a crucial factor. Attitudes ranged along a continuum, as follows:

- Recognising that the person had the right and ability to make choices and supporting her to do so;
- Assuming that the person had no clear or strong preferences and would fall in with whatever was suggested or decided on her behalf;
- Accepting that the person was expressing preferences, but that she was ‘wrong’ or misguided in her choice;
- Seeing the person as unable to make a choice at all.

Additional limitations on people making choices included: the ways in which these were provided, inadequate resources, families’ and professionals’ anxieties about risk-taking, and information being withheld from individuals about important changes in their lives. Sometimes participants were asked questions about their preferences in rapid succession and, if no answer was forthcoming, the question was rephrased and repeated. A participant’s failure to
respond, or delay in responding, could be misinterpreted as an absence of preference. Some individuals needed practical ‘tasters’ to try out different options and some required one-to-one support to do the things they wanted. Such resources were not always available. Participants were often denied choice when relatives or professionals felt the potential for negative consequences arising from the chosen activity was too great.

A further barrier to choice-making was the lack of information provided to participants about two key events in their lives – the death of a loved one and a diagnosis of dementia. Without such information, it was difficult for some participants to make appropriate decisions. Unresolved bereavement appeared to be an important issue for several participants. Furthermore, some individuals were being, or had been, assessed for dementia soon after experiencing bereavement.

Supporting choice
Supporting people with learning difficulties and dementia to make choices is not necessarily complex or difficult. It may, however, take time. A number of practical pointers emerged:

Communication
Effective communication is the key to increasing choice. Communication is both verbal and non-verbal. Body language often gives a clue to an individual’s preferences. It is important that attention is paid to these ways of communicating when considering the choice available to, and expressed by, people with learning difficulties and dementia:

When Phil went for a walk with one of the research team, he walked very slowly and his breathing appeared laboured. The following week, however, when the researcher asked if he wanted to go for a drive, Phil bounded down the steps and into the car.

Risk tolerance
Relatives and professionals may need to place greater weight on allowing individuals to take risks and less on ensuring protection. Where risk avoidance is given priority, there may be opportunities for minimising the risk associated with certain decisions rather than restricting the opportunity to decide.

Jane was fond of going to the shops by herself. Her keyworker speculated that this might be seen as risky, since Jane might be mugged, have her money stolen, be run over or get lost. The first two risks were considered part of ordinary life, potential dangers that might confront anyone and not grounds for preventing Jane going out. The risk of being run over was minimal as the main roads between her house and the shops had underpasses. The final possibility – that Jane might get lost - was becoming a greater concern as her dementia became more pronounced. Nevertheless, for the time being this was judged an acceptable risk and not sufficient grounds to prevent her exercising her choice to go shopping alone.

Take enough time
People need sufficient time to take in information, become familiar with people and places and to express preferences or make choices. This has staffing and resource implications.

‘Knowing’ the person
Families who have had a continuous involvement in their relative’s life can be a valuable resource, particularly regarding how the individual communicates. There may be conflicts of interest, however, when a family’s preferences are different from those of their relative. In addition, there is a risk that family or professionals may wrongly assume that they can predict a person’s preference.

Offer practical tasters
Practical ‘tasters’ can be an effective way of involving people in both day-to-day and major life decisions. Tasters can make a choice meaningful for an individual as s/he can experience the options offered and decide which s/he prefers. They can, however, pose a dilemma when a taster is imposed against a person’s expressed wishes:

Ann, the day centre officer, described how she ‘forced’ people to go on a trip outside the centre once a week, although they regularly objected to doing so, with some people actually being put on the bus in tears. Once on the trip, they invariably enjoyed themselves but had forgotten that fact by the following week, when the scene was re-enacted.

Conclusion
People with learning difficulties and dementia often have clear preferences. On the basis of this small-scale, in-depth study, the researchers conclude that those involved need to become more aware of this fact and more responsive to individuals’ choices. It may be helpful for professionals and carers to review their own behaviour and attitudes and how these may restrict the choices available to people. The researchers suggest that reviewing the following areas would be helpful:

Managing bereavement
People with learning difficulties, whether or not they have dementia, need clear information about the fact and circumstances of a loved one’s death and to be supported through bereavement. This is not a good time for anyone to make major life decisions. Instead, individuals need plenty of time to grieve and only later be encouraged to make choices about the future.
Managing dementia assessment and diagnosis

Professionals, families and people with learning difficulties themselves all need clear and accessible information about dementia and people with learning difficulties. This needs to include factual information about the assessment process, the implications of diagnosis, and dementia services and how to access them.

People who are undergoing assessment for dementia and/or have been diagnosed as having the condition, need sufficient information in an accessible format on which to base their choices. However, the study also showed that it is important to give careful consideration to a number of factors about the individual and her likely response when judging whether or not to tell people they are being assessed for dementia, or that they have a diagnosis of dementia. Individuals informed of the diagnosis need sensitive support to help them understand and come to terms with this major change in life circumstances. They may also need support to help them to make long-term decisions and settle their affairs:

“If you’re in the late stages of dementia and you’re told you’ve got dementia, you’ll forget anyway. If you’re in the early stages and you’re diagnosed, I’ve known people to take deep depression and go into denial. So I would say to judge the individual person and get as much information on that person from carers, family, friends to see how they would handle it.” (Keyworker)

Training implications

People who work with and support individuals with learning difficulties are likely to need training on dementia issues. In particular, there should be an emphasis on recognising and maximising people’s abilities, including their choice-making skills and how to help preserve these.

Other implications: staffing, resources and continuity

Several of the practical steps outlined above have staffing and resource implications. More time – to enable effective communication, to build up trust and an understanding of the individual’s communication methods, hopes and preferences – is vital. Continuity – of staff, of housing and support more generally – is very important, particularly when major life changes are occurring.

About the study

The researchers talked to twenty people with learning difficulties who either had a diagnosis of, or were currently being assessed for, dementia. These individuals lived in a variety of settings and were visited on several occasions. The researchers used a range of methods to learn about choice-making opportunities in people’s lives, including talking to participants and spending time with them. The latter was particularly useful for those participants who did not use speech to communicate. The researchers also interviewed a professional or keyworker involved in supporting each person and, wherever possible, a family relative as well. The visits were conducted during 1998. Where appropriate, the discussions were audio-taped and later transcribed. In addition, field notes were made. Both sets of qualitative data were analysed for recurring themes. The study employed a research reference group made up of people with learning difficulties who offered advice on various aspects of the study.

How to get further information

The full report, Going with the flow: Choice, dementia and people with learning difficulties by Kirsten Stalker, Paul Duckett and Murna Downs, is published for the Foundation by Pavilion Publishing (ISBN 1 84196 004 7, price £10.95).