

## Adults with learning difficulties' involvement in health care decision-making

A 1999 Department of Health publication, *Once a day, one or more people with learning difficulties are likely to be in contact with your primary healthcare team. How can you help them?*, contains a section about consent to medical treatment. New research suggests that custom and practice surrounding consent does not serve adults with learning difficulties well. Researchers from the Institute of Medicine, Law and Bioethics at the University of Liverpool and the National Development Team found that:

- f** Most of the people with learning difficulties interviewed relied on others to support their contact with the health service. Only those who lived independently had real opportunities to access services on their own.
- f** Families and care-givers had a great influence on people's health-care decision-making. On the positive side, this could give people the confidence to explore options and make decisions. It could also ensure that people were understood and could understand. On the negative side, professionals tended to look automatically to care-givers to take decisions, undermining any possible involvement by people with learning difficulties. Many people with learning difficulties interviewed felt that professionals did not listen to them.
- f** Both professionals and relatives had misconceptions about the ability of care-givers to give 'proxy' consent on behalf of adults with learning difficulties. People were often excluded from even very basic decision-making, such as choosing spectacle frames. Some professionals refused to treat people with learning difficulties at all.
- f** People with learning difficulties had been given very little accurate information about general health issues, such as contraception or routine screening, and sometimes had been given completely misleading information. This limited their ability to make decisions on health-care.
- f** There was no evidence of people's competence to consent to medical treatment being routinely assessed. Decision-making seemed to have been based in most cases on the assumption of incompetence, regardless of context.

## Introduction

Both debates and literature about health-care decisions by, with and for adults with learning difficulties are generally limited to such controversial issues as sterilisation, abortion and the withholding of life-saving treatments. Decision-making about routine and less extraordinary treatments has not received much attention. The part that adults with learning difficulties play in making decisions about their health and how these decisions are made by, with and for them is less explored.

This study started from the viewpoint that people with learning difficulties' perspectives on decision-making in health care are essential if understanding and practice about consent is to be improved. Accordingly, in 1998, the research team met with adults, parents, relatives, paid care-givers and self-advocates to find out about their experiences and identify how decisions about health care are made.

## Accessing health services

Adults with learning difficulties face a number of health problems. Many people do not tell others of their illness and some have difficulty in communicating with health professionals and carers. They are also more likely to have higher levels of physical and sensory impairments and physical and mental health problems as they grow older. Their relatives may avoid health services if the person with learning difficulties has behaviour problems. Health professionals may also see people's illnesses as related to their learning difficulty and decline to treat them.

Most of the people interviewed relied on others to arrange or support their contact with the health service. In a health service which relies on people identifying their own needs, people who have difficulties in communicating with others or find it hard to explain how they feel are necessarily disadvantaged. Certainly, adults with multiple impairments and extensive support needs routinely required the help of others to enable them to access services and to articulate their health care choices. Only those who lived independently seemed to have real opportunities to access services alone.

The influence of families and care-givers on people's health care decision-making is immense.

"You get letters so you go with your Mum."

On the positive side, this gives people encouragement and confidence to explore options and make decisions. It also makes sure that people are understood and that they can understand. As one parent explained:

"I'll always go down because sometimes she can't grasp what they're saying. And then what I do when I come out the surgery, explain things to her."

Many parents and care-givers identified themselves as the primary decision-makers for adults with learning difficulties. Their beliefs and attitudes influenced the opportunities of adults with learning difficulties to make decisions. This role could sometimes be a chance to exert control, as one woman described:

"I wanted some new false teeth but my brother wouldn't let me. He said it would make my face sore."

Some adults with learning difficulties experience difficulty in reconciling conflicting influences and may feel pressurised into making health-care decisions in order to please their relatives and care-givers. Good practice would suggest that if part of the reason for refusing treatment is family influence, taking steps to address the concerns of the family as a whole may provide one way forward. Similarly, providing real opportunities for independent access for people with learning difficulties may offer further improvement to current practice.

## The attitudes of professionals

Some professionals refuse to accept adults with learning difficulties as patients. As one care-giver reported.

"We went to the dentist's and I didn't even see him. His assistant came out and said 'We can't treat her.' So now we go to the Dental Hospital. They're really good there. I wouldn't have minded if I knew that the dentist didn't have the facilities but I knew he did."

'People don't listen to you' was a comment frequently made by people with learning difficulties. Perhaps health professionals are so accustomed to dealing with people's families that they do not see the need to address their patients directly. Some relatives similarly perceived this as unhelpful:

"They said she was 'confused'. She's not confused. She's really intelligent and can understand a lot."

It seems that if adults with learning difficulties are not helped to participate in health-care decision making, then decisions will be made for them, thus bypassing any consideration of their ability to give consent.

## What kinds of decisions are people making?

Many people were completely excluded from health-care decisions, ranging from general health screening to reproductive health. Some women appeared to reject implicitly the idea that they might make their own decisions about their reproductive futures:

"[My Mum] said not to go out with boys and that and she wouldn't let me get married ... I had to go on the needle so I wouldn't have no children. She wouldn't look after any children what with Dad being ill."

It seemed that relatives and care-givers often overstep the boundary between supporting adults to make decisions and acting as the decision-maker. This proxy decision-making even encroaches into the more routine matters, with few adults choosing their own spectacle frames, for example. This shows how far away from decision-making some adults are. It is hard to believe that many adults with learning difficulties would not be competent to indicate which frames they favoured. Not being used to making decisions in the more mundane, non-invasive forms of health care leads to a situation where people do not make decisions; the fact that they do not make decisions then becomes the rationale for not consulting them.

All workshop participants were clear that their views and decisions should not be ignored:

"I would tell them [people with learning difficulties] they can make up their mind because it's their decision. It's their decision."  
(Woman with a learning difficulty)

However, the adults with learning difficulties found it extremely hard to assert themselves when they were being ignored in clinical settings. It was not possible to find out whether workshop participants who had been excluded from decision-making had been deemed incompetent in law to give consent to proposed treatment at the time the decisions were made. Only when adults lack 'mental capacity' (that is, are unable to comprehend and retain information that is material to the decision, including the likely consequences of having or not having the proposed treatment, or are unable to use the information and weigh it in the balance as part of the process of arriving at the decision) can they be prevented from making their own health-care decisions unaided. In such instances, health-care interventions can take place if they are in that person's best interests.

In the context of the workshops and interviews, many appeared to understand the purpose of their

health care, even though they had played no meaningful part in the health decisions they described. This may show that adults with learning difficulties are prevented from making their own health decisions because health professionals do not always provide access to information. Similarly, some people are unable to make decisions because relatives and care-givers are not able to provide effective support.

## The consequences of limited knowledge

Having information about the nature of treatment is one of three elements of the ethical criteria for 'informed consent', along with voluntariness and competence. Yet it appeared that one of the workshop groups of adults with learning difficulties had not had much access to usable information about their health. As a result, discussions about health-care decisions were limited as the researchers tried to identify people's information needs and misunderstandings:

"I wouldn't be able to [have children] being an epileptic."

"The Women's Group over the road said that we couldn't go near lads because they'll give us babies."

Few people had any understanding of intimate health checks, such as cervical screening, breast and testicle examinations. Few had received formal sex education and no one could remember classes at school about this. Most women appeared to rely on their mothers for information, although the female relatives and care-givers interviewed felt reluctant and uncertain about giving such information. Although the women's knowledge of sex was sparse, that of male participants appeared even more limited. They had received no sex information or information about keeping safe in sexual relationships.

## The complications of some 'choices'

The study revealed several 'choices' which were not designed to develop healthy lifestyles or improve health care:

"She has a dual diagnosis and is clinically obese. She attacks other residents, chooses to stay in bed all day then, when she gets up, she eats compulsively. She's incontinent of urine and that isn't helping her ulcers."

Competent patients have the legal and moral right to refuse medical treatment, even if others disagree with this or consider the refusal contrary to their 'best interests'. Most competent patients, however, do not

refuse all aspects of medical treatment. It seemed that the process of making 'choices' that lead to self-neglect is not specific or explicitly discussed with people's GPs or members of Primary Care Teams. Using choice as a reason for non-intervention in *all* health care situations may signal a departure from the legal and ethical duty of care that is owed to vulnerable adults when there has been no assessment of a person's ability to make a particular health-care choice. Strikingly, there was no evidence of fall-back positions that provided *some* health care, even though no one with a learning disability had declined *all* possible interventions.

### Forfeiting decision-making

There was an overriding view that relatives and care-givers are entitled to make decisions on behalf of adults with learning difficulties and this was reinforced, in part, by prevailing health-care practice. Some parents and care-givers were invited to sign consent forms, agreeing to medical treatment on behalf of adults with learning difficulties, even though such 'proxy' consent has no validity in law. The symbolism of this was not lost on some workshop participants who believed that the decisions of relatives and care-givers would be more important than their own wishes. Many believed also that family members could veto treatment concerning reproduction. This perception is not grounded in law and yet is perpetuated by the practice of presenting consent forms to parents and care-givers.

Neither workshop participants nor interviewees described processes which could be identified as competence assessments to consent to medical treatment. Significantly, no one referred to 'holding' or low-risk interventions, allowing people time to think about the risks and benefits of particular treatments. Ordinary episodes of day-to-day health care decision-making were invaluable in exposing the attitudes of 'knowing' others, including health professionals. It appeared that unchecked assumptions about people's competence stray into areas where incompetence does not exist. In turn, opportunities to become more effective decision-makers are denied.

### About the study

The study was carried out by Kirsty Keywood and Sara Fovargue of the Institute of Medicine, Law and Bioethics and Margaret Flynn of the National Development Team (NDT). It was prefaced by summaries about the intended study in the NDT's

newsletter *Soundtrack* and the University of Liverpool's newsletter *Precinct*.

Two groups of adults with learning difficulties in Liverpool and Sefton were identified. With the help of link workers in each location, the groups embarked on a series of seven workshops which explored an array of medical treatment circumstances all of which vary in the demands they make on decision-makers. Separately, parents, relatives and carers were interviewed and at the conclusion of the workshops, members of two advocacy groups, one based in a day service, were also interviewed. Transcriptions of the workshops, shared with participants at every meeting, together with transcriptions of the interviews form the basis of the full report.

### How to get further information

The full report, **Best practice? Health care decision-making by, with and for adults with learning disabilities** by Kirsty Keywood, Sara Fovargue and Margaret Flynn, is published by the National Development Team (price £5 plus 50p postage and packing). It is available from St Peter's Court, 8 Trumpet Street, Manchester M1 5LW (Tel 0161 228 7055). The report is free of charge to people with learning difficulties, their parents and unwaged carers.

For further information about the research please contact Margaret Flynn at the above address and Kirsty Keywood at the Faculty of Law, University of Liverpool, L69 3I3X.