

Demonstrating control of decisions by adults with learning difficulties who have high support needs

Choice and control are at the heart of developments for people with learning difficulties. The recent White Paper, *Valuing people: A new strategy for learning disability for the 21st century*, acknowledges this in its key principles. People with high support needs (who may be labelled as having severe or profound learning difficulties and may also have physical and sensory impairments) may find themselves excluded from these developments. Research by Values Into Action investigated how decision-making can be supported and demonstrated. The researchers found:

f Some people with learning difficulties and high support needs received good support to make choices and be in control of their lives. Among the factors enabling this were:

- ways of working that actively facilitated the 'supported decision-making' model, particularly around good communication and relationships;
- a focus on the process of decision-making, rather than on assessments of capacity to decide;
- a rigorous approach to building evidence of the process, including careful and creative recording and monitoring.

f Some people were not supported to have effective choice and control over their lives. Reasons included:

- negative assumptions that people could not make choices;
- organisational systems and structures that reduced choices to a fixed menu;
- poor staffing levels and low awareness of supported decision-making;
- service cultures and staff fears that set aside people's wishes and feelings where there were contentious issues or perceived risks;
- lack of independent advocacy;
- concerns about the law around decision-making and capacity, and lack of knowledge about legal rights and systems.

f The researchers concluded that:

- advocates, managers, staff and family members need better information about the supported decision-making model and people's legal rights;
- legal change around decision-making is required that revisits the concept of capacity and provides a clear legal framework for the use of 'supported decision-making'; this needs to go beyond 'substitute decision-making'.

Background and policy context

Choice and control are at the heart of modern developments in opportunities and services for all people with learning difficulties. Examples from policy initiatives include the recent White Paper from the Department of Health, *Valuing people: A new strategy for learning disability for the 21st century* (2001), and the Scottish Executive's Review of Services for People with a Learning Disability, *The same as you?* (2000).

"We believe that everyone should be able to make choices. This includes people with severe and profound learning disabilities who, with the right help and support, can make important choices and express preferences about their day to day lives."
(*Valuing people*, Department of Health 2001, p.24)

However, people with high support needs (who may be labelled as having severe or profound learning difficulties and, sometimes, also physical and sensory impairments) may find themselves excluded from these developments. Choice and control can be a matter of 'pot luck'. Many people find their opportunities restricted by other people's assumptions. Previous research by Values into Action (VIA) found that inaccurate assumptions or concerns about demonstrating an individual's ability to choose and control a direct payment meant that many people with learning difficulties were effectively excluded from direct payment schemes ('Implementing direct payments for people with learning difficulties', JRF *Findings*, March 1999, Ref: 349).

This research, based in England and Scotland, aimed to observe the decision-making process to determine how 'supported decision-making' (not 'substitute decision-making') could be rigorously undertaken and recorded, thereby giving it weight in both service and legal contexts.

The supported decision-making model

The research explored use of a model of decision-making called 'supported decision-making'. This starts from the following assumptions:

- All human beings communicate.
- All human beings express choices and preferences about their lives.
- These choices and preferences are the building blocks of decisions.
- When people's choices and preferences directly lead to action, this means someone is controlling

their own life, even if they need substantial help to make their choices happen.

The key role for supporters is not about making decisions on someone else's behalf ('substitute decision-making') but effective communication and relationship with the person they are supporting to enable their choices and wishes to directly affect decision-making. Capacity becomes an irrelevant concept in this approach.

Enabling people to be in control

The research found it was possible to support people with a learning difficulty and high support needs to be in control of their life.

Ralph carries a communication book around with him that explains how he communicates, and contains pictures and photographs to help him communicate. People he meets often, such as his music teacher, include relevant pictures. He can point at the large wipe-clean pictures to indicate that he would like something, or pick out photos of friends, family and staff. This book is reviewed regularly by his keyworker and other staff members. Ralph has a busy social life and his book is very useful when he meets new people.

Several factors seemed essential in supporting people with learning difficulties and high support needs to make choices and take control:

- Seeing decision-making as a process involving everyone, not a 'test' that the individual has to pass.
- Involving individuals in choice and decision-making at all times.
- Involving the individual's supporters (whether friends, peers, family, advocates or staff) in supporting decision-making.
- Routinely using imaginative, effective ways of communicating.
- Simple, appropriate language, accessible information and suitable decision-making environments.
- Collaborative teamwork and collective responsibility for recording evidence of choices.
- Recording the decision-making process in detail, using imaginative methods (photographs, pictures, multi-media).
- Active efforts to maximise the range of options available to people.

- Reviewing decisions, outcomes and the individual's satisfaction with these.
- Using formal decision-making systems (e.g. independent living trusts) when appropriate.
- Easy-to-use systems to challenge the decision-making process and its outcomes.

In terms of the legal aspects of decision-making, the following factors seemed crucial:

- A position of respecting and promoting people's legal right to make their own choices and control their lives.
- A presumption by everyone involved that the person can legally consent to, and control, decisions.
- Active steps by everyone involved to enhance the person's capacity to formally and legally make their own decisions.
- Formal assessments of capacity were used rarely, and with great caution, not as a way of 'passing the buck' where there were contentious or difficult choices.

Limits to choice and control

"None of these organisations think I understand. They don't understand! They say who you should work with and you have to stick with it." (Daniel, who has learning difficulties and high support needs, talking about his service)

Other people's assumptions and the structural factors of service organisations were much more likely to restrict choice and control than any characteristics of the individual.

Sometimes staff or family members doubted the individual's ability to communicate and express preference. Such assumptions were likely to be self-fulfilling as well as inaccurate: where people did not have the opportunity to learn about choice and control, it was unclear how they could demonstrate their ability to do so.

The main structural factors that limited choice and control were:

- Poor staffing levels, giving staff little time to develop communication and relationships with individuals.
- Fixed organisational procedures and paperwork, e.g. around money.
- Organisational culture that inhibited staff from taking risks.

- Lack of staff training and knowledge about person-centred techniques and the supported decision-making model.
- Lack of staff or family awareness about legal rights, the legal system, and how to challenge formal systems of decision-making.
- Lack of independent advocacy for people with learning difficulties.

Problems with the current legal context

As part of the research, the current legal context around decision-making in England and in Scotland was explored to see how it helped or hindered use of the supported decision-making model.

The researchers identified a key difficulty with the emphasis on the legal concept of capacity. Legally, people either have capacity to make a particular decision or they do not have capacity. Capacity is rarely tested in a court of law. Most often, assumptions about capacity are made by staff and family members without any formal assessment. Where formal assessments are made, they may be carried out by a professional (e.g. medical professional) with little or no information, communication or relationship with the individual.

The research found evidence that agencies, such as the Benefits Agency and the Court of Protection, made judgements about capacity without meeting the individual concerned. These judgements sanctioned substitute decision-making powers, whereby control was taken away from the individual and formally given to someone else. It was rare for substitute decision-makers to be monitored, challenged or held accountable for the decisions they made 'on behalf of' someone else.

In some cases, a formal assessment of capacity, or concerns that such an assessment would demonstrate 'incapacity', directly contradicted an individual's own choices.

Nina does not communicate using words. Over three years, staff had supported her relationship with her boyfriend. The question of Nina's 'capacity' to enter into the relationship never came up: it was clear Nina wanted to be in the relationship. However, when Nina's boyfriend asked her to marry him, staff panicked and called in a nurse from the community learning disability team. The nurse, who did not know Nina at all, did not know if Nina could consent. Her advice to staff was 'to leave it all alone'. This withdrawal of support effectively ended Nina's relationship.

For professionals working with a person-centred approach, an individual's preferences (which can be expressed in a variety of ways) are accepted as genuine choices to be built on when planning services and support. The legal concept of capacity seems to work against this by providing a legal basis for excluding some people from controlling their lives, through defining them as unable to make decisions.

Implications for the law around decision-making

Current developments in the law around decision-making (e.g. Adults with Incapacity Act (Scotland) 2000 and the position statement *Making decisions*, Lord Chancellor's Department, 1999) aim to bring about better substitute decision-making, and do not address the concept of capacity itself. However, this research suggests that the legal concept of capacity may work contrary to people's rights to choice and control, and also to how decision-making happens in 'real life'. Currently, there would seem to be a clash between the supported decision-making approach and the current legal system on decision-making.

About the study

The research was carried out by James Edge of Values Into Action. Seventeen people with high support needs, living in nine different homes in four areas of England and Scotland, took part in the research. Places and people were chosen to represent a wide cross-section of geographical location, types of living and support arrangements, cultural and other factors.

The research involved in-depth semi-structured interviews and observations with each participant over the course of several months. Interviews and discussions were also undertaken with each person's supporters (staff, family and friends). Observations of people being supported to make decisions and be in control of their lives were recorded. Additional information was gained through documentation on service policies and procedures, visits to other key organisations and existing literature.

How to get further information

The full report, **Who's in control? Decision-making by people with learning difficulties who have high support needs** by James Edge, is published by Values Into Action (ISBN 0 903945 56 8, £8.00 plus £1.50 p&p). Copies can be ordered in writing from Values Into Action, Oxford House, Derbyshire Street, London E2 6HG, Fax: 020 7729 7797, Email: publications@viauk.org.

A *Plain Facts* summary of the findings for people with learning difficulties is available from Pavilion Publishing, 8 St George's Place, Brighton, BN1 4GB, Tel: 01273 623222, Fax: 01273 625526. Self-advocacy groups can receive *Plain Facts* direct from the Norah Fry Research Centre, 3 Priors Road, Bristol, BS8 1TX, Tel: 0117 923 8137.

For further details about this project and VIA's work on decision-making, contact Catherine Bewley, Deputy Director, Values Into Action at the above address, Tel: 020 7729 5436.