People with intellectual disabilities have the right to make their own legally effective decisions whenever possible. This right is protected by the UN Convention on the Rights of Persons with Disabilities (UN CRPD) and the Mental Capacity Act 2005 (MCA). The UN CRPD says that disabled people have the right to equal treatment under the law, and the right to support in making their own legally relevant choices. The MCA says that people with intellectual disabilities must be given all practicable support to make their own decisions before they are considered to lack the capacity to make that decision.

The term ‘intellectual disability’ is used here to refer to a range of learning disabilities, brain injuries, and other cognitive impairments. This term aims to be inclusive of people with a wide range of disabilities that affect their thinking and communication skills.

The Everyday Decisions project looked at how intellectually disabled people in England make everyday legally-relevant decisions in and about their lives, and how well these decisions are supported by social care professionals. The research explored supported decision-making across a wide range of life contexts, including everyday choices about food, clothing and activities, life choices about education, employment and housing, more difficult decisions about financial, healthcare and legal matters, and relationship and friendship choices.

Harding and Tascioglu found that there is a great deal of excellent supported decision-making practice happening in front-line care and support contexts. Intellectually disabled participants spoke extremely highly of the services and support they receive from care and support staff, care professionals, family members and peer networks. Despite the wide varieties of decisions and choices discussed in this research, both groups of participants shared important insights about how supported decision-making happens in practice and areas where practical changes, shifts in social attitudes or legal reform are needed to secure the rights of disabled people.

About the Research: 46 people were interviewed for the Everyday Decisions project: 15 intellectually disabled people, six supporters, and 25 care professionals. Intellectually disabled participants had a wide range of learning disabilities and/or brain injuries, and many also had physical disabilities. Some of the supporters were paid carers or personal assistants, some were volunteers and some family members. The care professionals who participated in the research were employed in roles from front-line care and support workers through to senior positions in care management and mental capacity assessment.
EVERYDAY DECISIONS: FOOD, LEISURE, ACTIVITIES

Front-line care and support staff were often extremely good at supporting intellectually disabled people to make everyday decisions. Nuanced, person-focused and multi-sensory communication techniques are regularly used by social care professionals to support choices about everyday matters. Care professionals rely on a range of strategies including scaffolding, providing memory and context, and devising decision-making structures to ensure everyday choices are both offered and respected. All of the intellectually disabled participants spoke of their daily choices and preferences. Many of these participants had very busy lives, and were supported to engage in a wide range of activities.

LIFE CHOICES: EDUCATION, EMPLOYMENT, HOUSING

Intellectually disabled participants were able to make their own choices about whether to go to college, what to study, and where they work. Many intellectually disabled participants worked part time, often on a voluntary basis. Most of those who worked would like more opportunities to develop their skills and to be paid for their work.

Decisions about housing and accommodation matters were more challenging both for disabled participants to make and for care professionals to support. This is because decisions about where to live are shaped by financial and practical concerns that were out of the control of the person, supporter or care professional.

DIFFICULT DECISIONS: FINANCIAL, LEGAL, MEDICAL

As the perceived complexity of the information involved in decisions increased, such as where people were required to make financial, medical or legal decisions, disabled participants expressed less certainty about decisions, and greater needs for support. In contrast, difficult decisions were less well supported, overall, than everyday decisions and care professionals often defaulted to using the ‘best interests’ framework under the MCA to make substituted decisions in these areas.

Disabled participants were well supported to manage their day-to-day finances but needed help to manage their broader finances well. Innovations like easyread bank statements made it easier for people with intellectual disabilities to manage their own finances. When financial power of attorney was discussed in these interviews, it most often arose as a result of experiencing

‘So we’re going to [the South Coast] because he loves the beach, and he also loves walking. He loves scenery. So, he’s got absolutely no verbal communication at all and yet he will go and stand on the edge of a waterfall or a mountain and just sit down and just stare out at the beauty of it. But that’s more about sort of trial and error over the years of trying different things.’

LESLIE, CARE MANAGER

‘I do college Monday and a Wednesday. I’m independent. I do enterprise activity… quizzes and that, sort of like that. Computers, IT suite like, yeah I do all that as well. [I go to the day centre] on Tuesday, Thursday and Friday so yeah. So I go voluntary work on a weekend [in a charity shop] Like polishing the rails and the shelves, and sometimes I do hoovering as well. I do quite, I did about five hours last week, I sometimes do three hours, and sometimes I do two hours.’

Winnie

‘Well me personally now I’m in a better frame of mind of how to handle money than I was say before [my supporter] came along. I have now learned a lot about how to budget things… and also like you say it’s peace of mind. I know I can go out and enjoy myself now more than what I ever used to do before. And that’s a total difference.’

GARETH
Decisions and choices around relationships and friendships were seen as very important to intellectually disabled participants in this study. In contrast, Harding and Tascioglu found that many social care professionals expressed discomfort discussing this aspect of disabled people’s lives, and usually avoided addressing the areas of intimate relationships and sexuality unless concerns over abuse arose.

Over half of the intellectually disabled participants in this research were in a current relationship. Living in an independent living context (with appropriate levels of support) appeared most conducive to developing intimate relationships and friendships for people with disabilities. Engagement with disability-focused community activities, particularly those involving the arts and sport were particularly helpful in offering opportunities for people with disabilities to form friendships and relationships.

Challenges in dealing with banks and financial institutions. Support with developing financial independence is also very important as a mechanism for disabled people to protect themselves from financial abuse.

Intellectually disabled participants in this research expressed a desire for more support from family, friends and professionals in thinking through legal decisions about future planning. Front-line care professionals generally reported not being involved in decision-making in these areas.

A key mechanism that intellectually disabled participants used to ensure that they were supported in medical decision-making was to attend medical appointments with either a member of their family or a paid support worker. Some intellectually disabled participants had formalised their support needs in the form of a health and welfare power of attorney.

In contrast, many of the care professionals in this research reported medical decisions being made using the ‘best interests’ framework under the MCA, rather than supporting disabled people to make their own choices about care and treatment.

‘My mum’s done the health [and welfare power of attorney] because when I go to the doctors I clam up, I struggle to explain myself, especially, and mum always talks to me. So in that sense, I mean last week, in fact last Friday… I’d got a bad tooth and I’ve had earache and everything. And [the dentist] wanted to do root canal treatment and I hadn’t got a clue. So my mum who was sat in the corner, I asked her to explain it to me.’

ALEX

‘I was always told in my life, when you went to a traditional day service you had to go by the rules, regulations. You couldn’t do anything out of context if you know what I mean. You’re always told what to do and you cannot do this, you cannot do that, and so forth. But when the opportunity of looking at having an organisation which people with learning difficulties can have for themselves, and choose their own support and develop their own skills and run it, it was a different meaning.’

GARETH

Independent advocacy services were highly valued by care professionals, especially when mediating between service users and their families. Care professionals tended to report utilising advocacy services when there was some form of conflict about a decision. A number of care professionals mentioned that it can be difficult to access independent advocacy services.

Many of the disabled participants in this research were involved with disabled people’s self-advocacy groups. These organisations, which are run by and for intellectually disabled people, provide important opportunities for disabled people to build decision-making skills, access appropriate support for everyday decision-making, and build supportive peer networks.
KEY RECOMMENDATIONS

The findings from this research into supported decision-making by people with intellectual disabilities led Harding and Tascioglu to make four key recommendations:

1. More training is needed within the care sector to improve general understandings of the UN CRPD and supported decision-making under the MCA.

2. Legal reform is required to embed supported decision-making more fully in practice, and to bring the MCA closer to CRPD compliance.

3. Nuanced support and communication approaches, building on strategies developed for everyday choices, should be utilised for more complex decisions.

4. More research needs to be done into supporting decision-making about finances, healthcare and legal future planning tools like wills, advance decisions and power of attorney.

REFERENCES


Everyday Decisions project website and blog: www.legalcapacity.org.uk
Everyday Decisions twitter: @legalcapacity

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