

Research finds people with intellectual disabilities not receiving support for big decisions

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Researchers from the University of Birmingham have found that people with intellectual disabilities receive much lower levels of support and guidance when making difficult decisions, especially those related to legal issues such as wills, advance decisions and power of attorney.

The new findings come from the "<u>Everyday</u> <u>Decisions</u>" project, undertaken by academics from University of Birmingham's, Law School. The project explored how people with <u>intellectual</u> <u>disabilities</u> make everyday decisions and how care professionals <u>support</u> them when they do.

The research looked at how <u>mental capacity</u> law works in practice, in order to identify good practice and where practical changes, shifts in social attitudes and legal reforms are needed to secure the rights of intellectually disabled people.

Although the requirements of the Mental Capacity Act (MCA) 2005 are enshrined in policies relating to providing assistance to people with intellectual <u>disabilities</u>, including those with learning disabilities and acquired brain injuries, current levels of support fall short of the expectations and requirements of the UN Convention on the Rights of Persons with Disabilities.

Professor Rosie Harding, University of Birmingham said: 'instead of offering more support for more <u>difficult decisions</u>, such as medical, legal and <u>financial decisions</u>, professionals often defaulted to making 'best interests' decisions.

"Capacity assessments were not always used on a <u>decision</u>-by-decision basis, with many frontline care professionals being uncertain about how to undertake them."

It was found that support around making other decisions, such as those pertaining to day-to-day activities, food and clothing, was very good.

The researchers also found that the tools developed in care practice to support everyday decisions could be extended to help intellectually disabled people make more difficult life choices and decisions.

Professor Harding added: "The implementation of aids and improved methods of communication were a step towards this goal. Other techniques involved education, skills development and 'scaffolding' people towards making their own decisions."

The researchers cited easy-read bank statements as an example of a simple solution making difficult activities, around managing finances, easier for disabled people.



Other key findings include:

- Community services aimed at disabled people, especially those run by and with them, like self-advocacy organisations, can make an essential contribution to helping people with intellectual disabilities build decision-making skills, access appropriate support for everyday decision-making, and build supportive peer networks;
- Formal independent advocacy services such as those provided by Mental Capacity Act Independent Mental Capacity Advocates (IMCAs) are highly valued by care professionals, especially when mediating between service users and their families;
- Greater awareness of the UN Convention on the Rights of Persons with Disabilities, training for care professionals in its requirements, and implementation of the changes proposed by the Law Commission in 2017 to the MCA's 'best interests' element would provide additional legal and policy drivers for extended support for decision-making.

Jayne Leeson MBE, Chief Executive of Changing Our Lives, a West Midlands-based organisation working in partnership with disabled people and those with lived experience of mental health difficulties, to find solutions to social injustice and health inequality, added:

"People with learning disabilities often find themselves trapped in situations where they are not afforded their basic human rights.

"Family members, professionals and staff working with the person are also ill equipped to enable the individual to act upon their rights, and the poor application of mental capacity legislation often compounds this situation.

"This is why research emerging from the "Everyday Decisions' project is of such importance as it shines a light upon these inequalities and suggests solutions that contribute towards a cultural shift where <u>disabled people</u>, families and professionals would have greater awareness of legal rights and

solutions."

Provided by University of Birmingham



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