Findings Summary

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The Everyday Decisions Research Project

The Everyday Decisions Project asked how people with learning disabilities or brain injuries make everyday decisions, both on their own and with support.

We wanted to find out how care professionals work with mental capacity law and to find out what works well and where things can be changed to help protect disabled people’s rights.

We were really interested in the Mental Capacity Act 2005 and the UN Convention on the Rights of Persons with Disabilities.
We were interested in lots of topics, including everyday choices about food and clothing; life choices like housing, education and employment, and difficult choices about money or medical and legal choices.

We also looked at relationship and friendship choices.

We found lots of really good work and lots of good care and support services.

Lots of disabled people who took part said they liked the services and the support they get from care and support staff, care professionals, family members and friends.
We also found some areas where law, practice or society need to change to better support disabled people’s rights.

What we found out:

- Lots of care professionals knew about the Mental Capacity Act and used it in their work.

- Not very many people knew about the UN Convention on the Rights of Persons with Disabilities.

- We found that lots of care professionals are very good at supporting everyday choices about activities, food, and clothing. Disabled people who cannot communicate well are supported to make choices about everyday things.
Disabled people told us they had control over some decisions about working and learning.

Decisions about where to live, and choices about housing were not very well supported. This was made more difficult by there not being lots of the right housing in the right areas.

Care planning was seen by care professionals as very important for supporting people with disabilities in making everyday and life choices.

Many disabled people we spoke to would like more opportunities to work. Sometimes they found that the benefits system made it difficult to work.
• Disabled people were supported to manage money on an everyday level.

• More difficult decisions about finances were often made as ‘best interests’ decisions, or with the help of a court-appointed deputy or a person with power of attorney.

• Being supported to manage money helped disabled people protect themselves from abuse.

• Easy read bank statements made it easier for disabled people to manage their own money.
Some disabled people took a supporter with them to medical appointments to help make decisions.

Some people thought that doctors did not explain things clearly enough.

Care professionals said that medical decisions were usually made by others in the best interests of the people they support.

The disabled people we spoke did not find it easy to get information about things like wills, advance decisions, power of attorney.
Some disabled people wanted more information and support in thinking about things like wills, advance decisions and power of attorney.

Care professionals said that they were not often involved in decision-making in these areas.

Care professionals did not often discuss issues relating to the relationships and friendships of the people they care for.

Half of the disabled people we spoke to had a girlfriend or boyfriend or fiancé.
Supported independent living, and taking part in disability-focused community activities, helped disabled people to form relationships and friendships.

Disabled people and their supporters told us that the benefits system was hard to use, and that sanctions were especially difficult for them. Sometimes the payment times for benefits made managing money more difficult.

Disabled people thought that community self-advocacy services were very important.

Care professionals thought that independent advocacy services were very useful, especially if there was a conflict between disabled people and their families.
Care professionals thought that sometimes they have to spend too much time doing paperwork, which stops them from giving the best care and support.

We found that there is a tension between supported decision-making and the Mental Capacity Act. This means that mental capacity assessments don’t always work the way they should.

Sometimes people are found to not be able to make decisions when they might be able to with good support.

Sometimes people are found to have the ability to make decisions when they can’t.
Our Recommendations (Things we think should happen):

1. There should be more training for care staff about the importance of supporting decision-making as a way of supporting legal capacity under the Mental Capacity Act.


3. Care professionals would like more training on the UN Convention on the Rights of Persons with Disabilities.
We think the Mental Capacity Act should be updated to give more weight to what disabled people want.

Care professionals and disabled people should be involved in updating the Mental Capacity Act Code of Practice.

Disabled people should be supported to make more decisions about housing, medical and legal choices, money, relationships and friendships.

Supporting legal capacity requires well funded support services for disabled people, including community services, advocacy and self-advocacy.
There needs to be more research about how banks support disabled people.

There needs to be more research about how disabled people can be supported to make medical decisions.

There needs to be more research about legal advice for disabled people.

As a society, we need to change our attitude towards friendships and relationships in disabled people’s lives.
Policy makers need to make the benefits and sanctions regime simpler so that people with disabilities can be better supported.

Disabled people’s self-advocacy organisations should be well funded because they provide important skills development as well as services.

Local and central government investment in care services should recognise the need for both high quality care-giving and care planning.

The Mental Capacity Act 2005 Code of Practice should be updated with more examples of how to support disabled people to make their own decisions.