

Summary

Does it matter? Decision-making by people with learning disabilities

About the DRILL Programme

DRILL (Disability Research on Independent Living and Learning) was an innovative 5 year, UK wide programme led by disabled people, for disabled people and funded by the National Lottery Community Fund.

Launched in 2015, the programme was managed by a partnership of Disability Action Northern Ireland, Disability Rights UK, Disability Wales and Inclusion Scotland.

The aim of the programme was to build better evidence about approaches which enable disabled people to achieve independent living. The findings from the projects it funded can be used to inform future provision across a wide range of policy areas, and give a greater voice to disabled people in decisions which affect them.

This is one of a series of summaries of the project supported by DRILL. Final reports, toolkits and summaries of all the projects are available from the DRILL website at www.drilluk.org.uk.

Overview of the project

This project explored how supported decision-making can be designed to replace substitute decision-making for people with learning disabilities.

Approach

The project conducted interviews by peer researchers with people who have a learning disability. Interviews were also conducted with specialists in policy and practice relating to incapacity in Scotland.

Focus groups were also carried out across Scotland, and follow up interviews from there with participants who wanted time to share their experience in more depth.

Findings

Participants talked about the day to day decisions they made themselves without any help and support. These included choices such as when to get up, what to wear, what to eat and when and where to go out.

A small minority reported that, generally, they don't make decisions for themselves. Instead, support staff or their parents make decisions for them. They described feeling stressed, nervous and scared when making their own choices.

Overall, participants were positive about making decisions themselves and that it was important for them to be independent and have freedom.

Decisions which participants reported receiving help with included managing money, shopping, choosing a place to live and finding information on the internet.

Participants reflected positively when asked how they felt about being helped and supported with decision-making. Having a relationship with the supporter was key to feeling reassured and calm.

Having support was helpful for bigger decisions, and for double checking intended decisions.

Some participants did report that support was annoying, or overwhelming. Most reported that they found it difficult to say no.

Decisions being made about participants, without asking them, included changing support, what to do each day and what medication to take.

Findings (continued)

These decisions made participants feel a range of negative emotions. They often felt that they would have made a different decision to the one which was made for them.

Participants had also sometimes been told they were not allowed to make some decisions. These included health matters, sexual relationships, travelling independently and what time to return to their residence.

Recommendations

The project outlined many recommendations, some of which are listed here. All recommendations are included in the full report which is linked below.

- There should be a presumption that an individual has decision-making capacity, until it is established that they do not
- Someone should not be treated as lacking decision-making capacity until all practical steps have been taken to help them make their own decisions
- Recognise that someone may have decision-making capacity for some matters and not others
- Decision-making capacity should not be determined on the basis of a person's appearance or the way they communicate
- A person who makes a decision that, in the opinion of others, is unwise does not necessarily lack decision-making capacity
- Information should be given in ways which are appropriate to an individual's abilities or circumstances
- A person should be deemed to have decision-making capacity for a matter if it is possible for them to make a decision with practical guidance and appropriate support.

Final report

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Please click on report name to read the full report.

Project partners

People First (Scotland)



Animate Consulting

