

Summary

Supported decision making – experiences, approaches and preferences

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

The project researched the experiences of people with mental health problems and learning disabilities of the decision making processes around living independently.

It looked for solutions to empower disabled people to directly influence decisions affecting them, from daily living to major life decisions.

Approach

The project used a qualitative research approach, conducting semi-structured interviews with 41 participants with mental health problems and/or learning disabilities, from across Northern Ireland.

Interviews were carried out by a member of the research team and a team of peer researchers, who had lived experience of mental health problems, or a learning disability, or both.

Findings

Decision making is a central aspect to people's lives. Participants reflected positively upon the role of the decision making, but also noted how it felt when there was a lack of support for this.

The research created a sense that many of the participants were relatively independent and comfortable making minor decisions. However, they welcomed support when required.

Decisions ranged from everyday decisions, such as routine, travel and finances to major decisions such as moving home.

The type of decision, the role of other people, and what the outcome might be all made decision making harder.

Participants said they would like practical support, such as more accessible information. They would also like emotional support and, sometimes, options to choose from.

The use of peer researchers in this project was valued by participants and strengthened the research process.

Time was considered an important factor in all decision making processes.

Participants with mental health issues cited their mood, a deterioration in mental health and the use of drugs and alcohol as impairing decision making. These participants highlighted the need for support when they were feeling 'unwell.'

Findings (continued)

Participants discussed occasions where decisions had been made for them. They described feelings of confusion, unhappiness and uneasiness.

Support was provided by family members, friends, support workers, health professionals and organisations. Participants recommended that these sources continue to provide support in the future.

The value of support from family, colleagues and peers was particularly highlighted.

Recommendations

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

- Support for decision making must be individualised and based on a range of factors such as the relevant information, the type of decision, the possible options and what the outcome might be
- Promote public awareness of the Mental Capacity Act (Northern Ireland) 2016, which provides a more comprehensive framework for formal decision making processes
- It must be explained to individuals whether there is an urgency to make a decision, or whether more time is available
- Use international exemplars to help inform guidance for supported decision making
- The ongoing development of the Code of Practice alongside the Mental Capacity Act (Northern Ireland) 2016 must consider the limitations and potential complexities of support
- It must be highlighted that what is intended to be support may, in some circumstances, move towards undue influence, coercion and/or abuse
- Consultation of people with experience of decision making will be a very useful aspect of the development of the Code of Practice
- There is an immediate need for research evidence on the effectiveness of the wide range of support interventions.

Final report

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Please click on report name to read the full report.

Project partners

Praxis Care



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