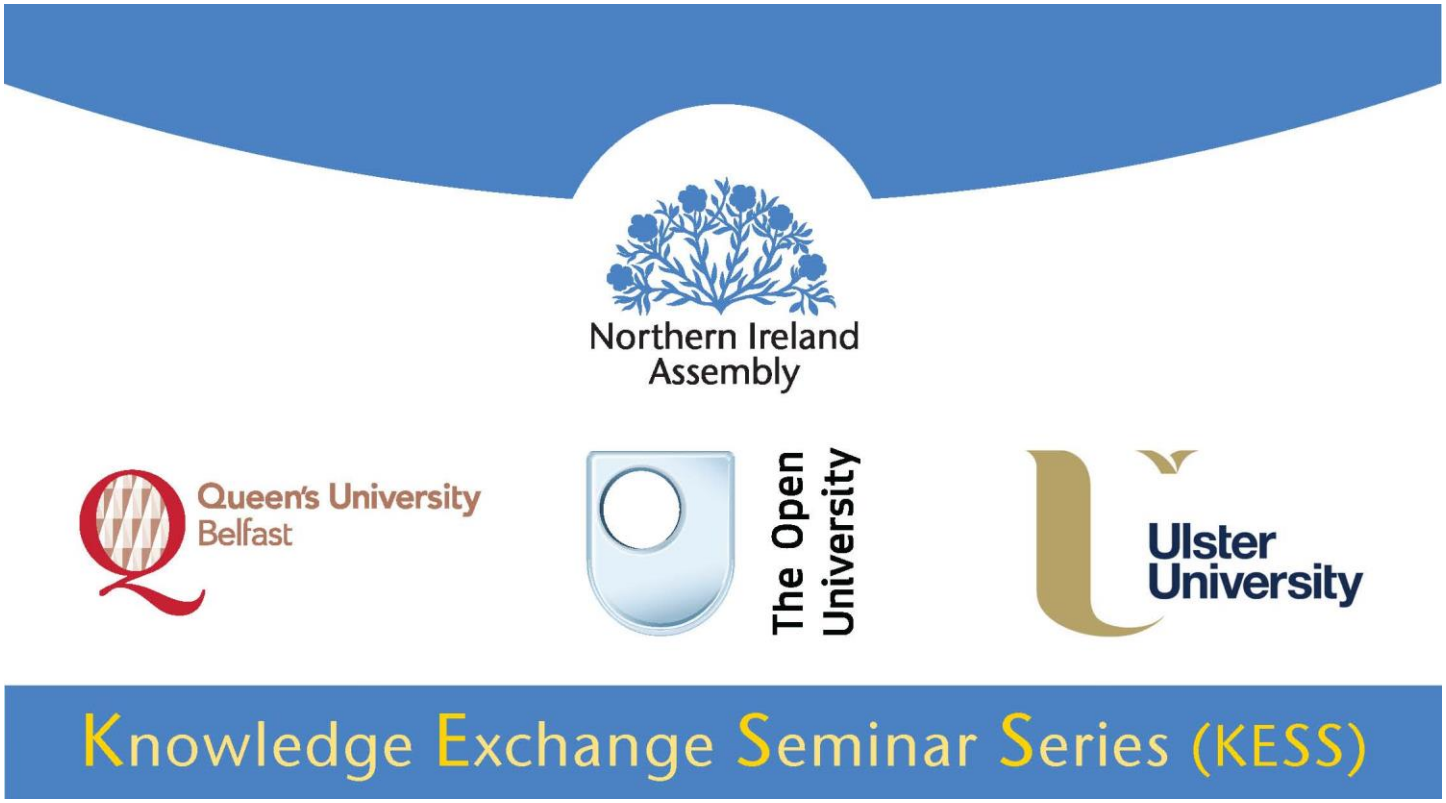

Supported decision making - experiences, approaches and preferences

Introduction

Making decisions about your own life is a key aspect of independence, freedom and human rights. Mental health law has previously allowed compulsory intervention even when a person has the decision making ability to decline intervention. This discriminates against those with mental health problems and intellectual disabilities. In May 2016 the Mental Capacity Act (Northern Ireland) became statute law although it may not be implemented until 2020/21. In contrast to other countries this law will replace rather than be in parallel to a mental health law. This is a unique and progressive development which seeks to address the discrimination of separate mental health law. A core principle of the new Act is that people are "not to be treated as unable to make a decision...unless all practicable help and support to enable the person to make a decision about the matter have been given without success" (Article 1(4)).

This research project explored how people have, or have not been, supported to make their own decisions. It aimed to provide an overview of the approaches to support that are possible and to find out from people what works for them. The findings can therefore inform how the new support principle should be implemented in practice.

What is Supported Decision Making

“Supported decision-making is a framework within which a person with a disability can be assisted to make valid decisions. The key concepts are empowerment, choice and control” (Carter, 2009, p. 9). Carter (2009, p.8) also refers to the United Nations Handbook on the Convention on Rights of Persons with Disabilities, which states: “Supported decision-making can take many forms. Those assisting a person may communicate the individual’s intentions to others or help him/her understand the choices at hand. They may help others to realize that a person with significant disabilities is also a person with a history, interests and aims in life, and is someone capable of exercising his/her legal capacity”. A further definition of supported decision making has been provided by the Victorian Law Reform Commission (2011, p.19), namely “An approach to decision making that involves providing a person with impaired capacity the support they need to make their own decision. It is often

contrasted with substitute decision making, where a decision is made on behalf of a person who is unable to make that decision".

What is the research issue?
There are people who, without support, would be assessed as incapable of making certain decisions but with the appropriate support are capable of making those decisions and so to not provide that support infringes their rights, undermines their autonomy and reinforces their exclusion from society.

Supported decision making should be considered as an important part of a continuum of decision making from autonomous decision making through to substitute decision making. Law and policy have tended to focus on either end of the spectrum and have approached capacity as if people are either globally capable or incapable, but most people require some level of support with decision making. The Mental Capacity Act Northern Ireland 2016 offers an excellent opportunity to create this comprehensive legal and policy framework.

There is very limited research evidence available about disabled people's experiences of the range of approaches provided to support decision-making; what approaches work for whom; and what people's preferences are for support. This evidence is urgently needed to inform the Code of Practice for the new Act and the wider implementation process.

The need for supported decision making
There are a number of rights based, effectiveness and pragmatic arguments for providing supported decision making.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) requires States to "take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity" (Article 12(3)). There are people who, without support, would be assessed as incapable of making certain decisions but with the appropriate support are capable of making those decisions.

Article 12(3) is the key reference to supported decision making, but the whole of Article 12 represents a paradigm shift away from the focus of policy and law being only on substitute decision making for people who are assessed as lacking the capacity to make a decision. The article requires the development of a positive range of supports to enable people to fully exercise their rights and, wherever possible, prevent the need for substitute decision making (Quinn, 2010).

The central principle underlying supported decision making is autonomy, that "no person should have another person appointed to make a decision on their behalf, if they could make the decision themselves with assistance and support" (Chartres and Brayley, 2010, p. 1).

The effectiveness arguments focus more on the benefits that supported decision making provides for individuals, families and societies. Chartres and Brayley (2010) suggest that supported decision making has three broad benefits. First, it can support personal autonomy, authority and control that people have over their own lives. Second, it can provide a clearer structure for individuals and families negotiating and making decisions and plans in the context of family, friends, informal carers and services. Third, they suggest that it can provide a more comprehensive means of ensuring people's legal and personal capacity to make decisions is promoted and respected. Chartres and Brayley (2010, p.32) go on to list the potential benefits for a person with disabilities as: "citizenship,

personal empowerment; self determination; self esteem; respect for decisions; control over their lives; confidence in decision making; confidence in rights; development of decision making skills and capacity; increase in areas of decision making; and increase in support networks".

The process of developing and implementing supported decision making will also provide societal benefits. Some of the dangers of not respecting people's rights to be fully included in society and not supporting people to make their own decisions have been demonstrated through the research on institutionalisation and the repeated inquiries into the abuse of people in care. The benefits to society of supported decision making include: contributing to a better and wider understanding of the importance of respecting the rights of all citizens; a more inclusive approach to disability; and generally enabling better decisions to be made.

The last benefit to society overlaps with the pragmatic arguments for supported decision making. These are based on the procedural justice research in mental health services which suggests that, in an assessment process, if people are listened to, respected and feel that their views are being considered, even if they do not agree with the outcome of that process, they are less likely to feel coerced and dissatisfied (McKenna et al., 2000; Galon and Wineman, 2010). In general terms, it seems reasonable to assume that if a person has received the support necessary to make their own decision, such as the type of service to use, they may be more willing to fully engage and benefit from that service.

Review of the current international evidence

A Rapid Evidence Assessment was completed using database and grey literature searches. The findings were mainly from North America, UK and Australasia. The review, which was presented at a previous Knowledge Exchange Seminar, suggests that it appears very difficult to ensure that good practice in supported decision making is consistently provided across all settings if it is not clearly required.

In England Chapter 3 of the Mental Capacity Act 2005 Code of Practice (Department for Constitutional Affairs, 2007) provides specific guidance on how people should be helped to make their own decisions. It suggests that the following points should be checked: Providing relevant information; Communicating in an appropriate way; Making the person feel at ease; Supporting the person. In Scotland there is guidance under the Adults with Incapacity (Scotland) Act 2000 relevant to supported decision making. Communication and Assessing Capacity: A guide for social work and health care staff (Scottish Government, 2008) aims to ensure all practicable steps have been taken to help the person make the decision.

There is a theme through the included studies of the need for staff training due to concerns about levels of knowledge; inconsistent practice; and the lack of involvement of service users (Goldsmith et al., 2008; Ahmed et al., 2011).

There is a wide range of strategies within supported decision making approaches. At the most basic level the provision of clear information and the simplification of decision-making tasks can provide support for decision making (Wong et al., 2000). Person-centred planning is also supported although there may be complexities in its implementation (Robertson et al., 2005; Dowling et al., 2007). Independent advocacy, representation and supportive networks can also be used to support people to make their own decisions and prevent the need for substitute decision making.

The full range of supported decision making is necessary as the need for supported decision making and the approaches that will be most effective will vary across people, time and decisions and so supported decision making, like capacity, should be viewed as decision specific.

The Mental Capacity Northern Ireland Act 2016 has the potential to provide a world-leading non-discriminatory and unified framework for supported decision making but evidence is now needed to inform the implementation of the Act.

Methodology

The need for this research was identified by analysis of the international research literature, the legal developments in Northern Ireland and through consultation with the service user fora in Praxis Care and Mencap. The approaches taken to supporting disabled people to make all the relevant decisions about their lives have been highlighted as a priority.

The research team is made up of: Paul Webb, Project Lead and Research Manager at Praxis Care; David Falls, Peer researcher Praxis Care; Fionnuala Keenan, Peer Researcher, Praxis Care; Christine Mulvenna, Barbara Norris, Peer Researcher, Mencap; Aine Owens, Peer Researcher, Mencap; and five researchers from Queen's: Dr Gavin Davidson; Dr Rebecca Shea Irvine, Dr Berni Kelly, Dr Aisling McLaughlin and Dr Lorna Montgomery.

During the early stages of the research the team provided input and training to each other on a range of issues. The researchers from Praxis and Mencap provided expertise on the current issues in how decisions are supported, or indeed not supported, in mental health and intellectual disability services. This informed the development of the interview questions. The Queen's researchers provided research training for the peer researchers which included inputs on interviewing, ethics, analysis, report writing and self-care.

The project has also been informed at key points throughout the research process by an International Advisory Group which includes specialist disabled and non-disabled researchers with expertise in this area. The Advisory Group members are:

- Taryn McKeen, Mental Health and Capacity Unit, Department of Health (previously Tomas Adell, Mental Health and Capacity Unit, Department of Health)
- Keith Lynch, People First Scotland (who have also conducted research about supported decision making)
- Margaret Kelly, Director of Mencap NI
- Dr Nancy Hansen, Director of the Interdisciplinary Master's Program in Disability Studies at the University of Manitoba
- Professor Michael Schwartz, Director of the Disability Rights Clinic in the Office of Clinical Legal Education at Syracuse University College of Law, in New York State, where he supervises students in disability advocacy and teaches clinical skills and disability law
- Dr Lisa Brophy, from the Centre for Mental Health, Melbourne School of Population and Global Health, University of Melbourne and is also Director of Research for Mind Australia
- Professor Richard O'Reilly, a Professor of Psychiatry at Western University in London, Ontario and at the Northern Ontario School of Medicine. Professor O'Reilly has researched extensively in the area of mental health law

The main method used to find out about people's experiences, the approaches to support used and what works was in-depth, qualitative, semi-structured interviews with 41 people with mental health problems and/or intellectual disabilities Participants were interviewed by two of the research team and the transcriptions of each interview will be analysed independently by two members of the team. Data will be analysed with the help of the qualitative data software NVivo.

Framework analysis will be used to analyse the data. This involves a structured approach to analysis involving five main steps:
1. familiarization;
2. identifying a thematic framework;
3. indexing;
4. charting; and
5. mapping and interpretation
(Ritchie & Spencer, 1994)

In order to further increase the reliability and validity of the research findings the results of the data analysis will be presented to all those who were interviewed as part of the project to ask for their feedback and comments on the themes that emerge and the possible recommendations that could arise from them. Ethical approval was obtained through the School of Social Sciences, Education and Social Work's Research Ethics Committee.

Initial findings
Data collection was completed in January 2018 and so this seminar is a presentation of the initial themes identified from the interviews.

In terms of people's experiences of decision making there was a wide range reported:

Nobody makes my decisions now, I make my own decisions, for years and years people did make decisions for me.

Well, I knew exactly what I wanted. The main problem was getting them to understand but I did know exactly what I wanted, there was no doubt in my mind what I wanted, and that I was pursuing the only course I could to change the situation and how it worked for me, you know.

I find it very hard to make a decision, it's like, you say something and I'll agree with it or I won't agree with it so it's like being given a multiple choice, what would you like? For I find it very hard to make a decision on my own.

Sometimes they are hard like you know. Putting things off, putting that off, I'm always putting things off usually you know.

Sometimes scared because I don't really know … sometimes I don't really understand … there's ways of going about different things and sometimes I don't know if I'm going to make the right decision, so … Sometimes I find it hard to ask my brothers and sisters in case I can't do something – I can, but I just don't understand what way to do it, so I don't.

Mmm … not understanding things, or things being … mmm … laid out in a different way that I'm not used to. Or decisions that mmm …. That has to be made quickly – that's confusing sometimes – because you have to think right on the spot and sometimes it's hard to think, because you … if I do that there, what's going to happen to this and that – so sometimes it's very hard …

So in the past, do you think you were given the opportunity to make decisions? *No, you didn't do nothing. You just sat about all day, you didn't have the chance to say, can I go for a walk? You were sectioned, you weren't allowed out of the building you know.*
And how does that make you feel when other people make your decisions?
It makes me feel angry and agitated.

Alternatively people did also experience that as supportive:
It makes me feel like that somebody is helping me.

It was also acknowledged that the outcome of the decision could impact on perspectives about the process: *Mmm … if it turns out a good thing then I feel good about it (laughs). So … that's all I can say about that.*

People also indentified a number of key components of support and ideas for how people should be supported:

Time… But I wouldn't take 'years' over it. I would think about it, reconsider it but I wouldn't make rash decisions... I would have to think it over. Time is a wonderful thing.

The main thing, I think what they should do, what should be added to people with mental health is a lot more family support….. I was just taken out of the house and then put into hospital and was told nothing, nothing was ever told, what was wrong with me or nothing, I mean my mum would come to the hospital crying and all, I didn't know what was going on and no one was telling anything because they 'didn't know' you know.

Give them more information – if you have all the information that's available, you're going to be in a stronger position to make a correct decision. I think that would be nearly the only requirement.

To have everything in accessible format, for that person to understand, and to define in what way it is best for that person to understand. So, one format isn't going to help everybody because everybody is different. So it's about making sure everything is set out in different ways for different people.

Just someone that you can talk to.

Next Steps

The main next steps in the research are to: further analysis the data, meet with participants to present and discuss the findings, complete and disseminate the research report. It is hoped that the findings will help inform the current drafting of the Code of Practice for the Mental Capacity Act Northern Ireland 2016 and the National Institute of Clinical Evidence's draft guideline on *Decision Making and Mental Capacity*.

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