



## Knowledge Exchange Seminar Series (KESS)

*...is a forum that encourages debate on a wide range of research findings, with the overall aim of promoting evidence-based policy and law-making within Northern Ireland*



# Supported decision making - experiences, approaches and preferences

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# Overview of presentation

- Context of the research
- What is Supported Decision Making?
- What is the research issue?
- Methodology of the research
- Initial findings from the interviews
- Peer researchers' reflections
- Implications for law, policy and practice



# Context of the research

- Making decisions about your own life is a key aspect of independence, freedom and human rights
- Our current mental health law allows compulsory intervention even when people have the capacity to decide
- The Mental Capacity Act Northern Ireland 2016 will introduce a new framework based on the need to respect everyone's rights and the need to support people to make their own decisions



# What is supported decision making?

“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”  
(Victorian Law Commission, 2011, p.9)

# Support principle

- The new Act introduces the duty to support people to make their own decisions
- Section 1(4) The person is not to be treated as unable to make a decision for himself or herself about the matter unless all practicable help and support to enable the person to make a decision about the matter have been given without success

# What is the research issue?

- There is some guidance available for how to do this (For example this Practice Framework (Bigby and Douglas, 2016))
- However, there is very limited evidence about people's experiences, and what works for whom in what circumstances



# Methodology

- Qualitative study of people's experiences of decision making, the approaches to support being used and what people's preferences are about support
- 41 in-depth interviews with people with mental health problems and/or intellectual disabilities
- Interviews conducted jointly, led by peer researcher supported by another member of the research team



# Data Analysis

Framework analysis will be used – 5 step process:

1. familiarization;
  2. identifying a thematic framework;
  3. indexing;
  4. charting; and
  5. mapping and interpretation
- (Ritchie & Spencer, 1994)





# Initial findings

- Decision making is a relatively abstract concept – applied examples are important
- 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.*
- *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.*

# Initial findings

- *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 ...*

# Initial findings

- 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 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.*

# Initial findings

- 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.*

# Initial findings

- *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.*



# Reflections on the peer research process

- Training
- Data collection
- Data analysis
- Dissemination
- Future plans



# Implications for law, policy and practice

- Code of Practice currently being developed by the Department of Health
- National Institute of Clinical Excellence also consulting on draft guidance on ‘Decision-making and mental capacity’
- Need for a better understanding of what works for people and for further consideration of the complexities of support



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