Supported decision making - experiences, approaches and preferences

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Overview of the presentation

* Research Team and International Advisory Group
* Rationale and context for the research
* Methodology
* Findings
* Implications for social work law, policy and practice

Research Team

* Paul Webb, Project Lead and Research Manager, Praxis Care
* David Falls, Peer Researcher Praxis Care
* Fionnuala Keenan, Peer Researcher, Praxis Care

* Christine Mulvenna, Communications and Events Manager Mencap NI
* Rosalie Edge, Community Support Officer, Mencap NI
* Barbara Norris, Peer Researcher, Mencap NI
* Aine Owens, Peer Researcher, Mencap NI

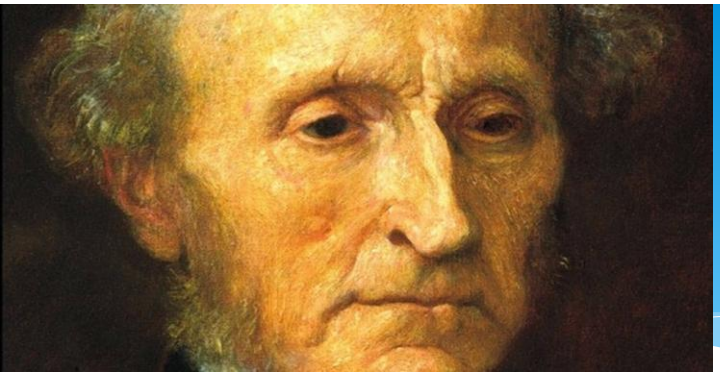
* Gavin Davidson, Professor of Social Care, Praxis Chair of Social Care, Queen's University Belfast
* Berni Kelly, Senior Lecturer, Queen's University Belfast
* Aisling McLaughlin, Research Fellow, Queen's University Belfast
* Lorna Montgomery, Lecturer, Queen's University Belfast
* Rebecca Shea Irvine, Research Fellow, Queen's University Belfast

International Advisory Group

* 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 had recently completed directly relevant research in Scotland 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
* Associate Professor Lisa Brophy, from the Centre for Mental Health, Melbourne School of Population and Global Health, University of Melbourne and is also Mind Australia's Principal Research Fellow
* Professor Richard O'Reilly, a Professor of Psychiatry at Western University in London, Ontario and at the Northern Ontario School of Medicine

Why did we do this research?

- Making decisions about your own life is a key part of **independence, freedom** and **human rights**
- Some people who lack the relevant decision making ability, with the right support, could make their own decision
- There is not enough evidence available about how to effectively support decision making
- The Mental Capacity Act (Northern Ireland) 2016 is a new legal framework for decision making when a person lacks the relevant decision making ability
- Social workers will be one of the key professions involved in implementation



Rationale

* "…the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant…
* It is, perhaps, hardly necessary to say that this doctrine is meant to apply only to human beings in the maturity of their faculties…Those who are still in a state to require being taken care of by others, must be protected against their own actions as well as against external injury."
* John Stuart Mill (1806-1873)

NI Context

* Current legal framework: Mental Health (NI) Order 1986 (criteria of mental disorder and risk) – possible to be detained with the relevant decision making ability; possible to be voluntary without the relevant decision making ability
* No current statute law to enable health and welfare decisions to be made for people who lack the capacity to do so – reliance on common law principles of necessity, reasonable belief and best interests – High Court if necessary
* ECHR/Human Rights Act Judgements – Bournewood - HL vs UK (2004)
* Developments in the laws of our neighbouring jurisdictions
* Dawson and Szmukler (2006) Fusion approach
* UNCRPD (2006) supported decision making
* Bamford Review (2002-2007)

Context – Mental Capacity Act (Northern Ireland) 2016

* Bamford Review of Mental Health and Learning Disability (2007) A Comprehensive Legislative Framework
* "The Review considers that having one law for decisions about physical illness and another for mental illness is anomalous, confusing and unjust…
* the Review considers that Northern Ireland should take steps to avoid the discrimination, confusion and gaps created by separately devising two separate statutory approaches, but should rather look to creating a comprehensive legislative framework which would be truly principles-based and non-discriminatory."
* Passed by the NI Assembly and received Royal Assent on 9th May 2016
* Draft Code of Practice – consultation with Reference Group September 2017 and formal consultation 2019
* Implementation planned for 2020/21
* (Assembly suspended January 2017)

Range of causes of impairment	Types of decision	Levels of intervention	Safeguards
Section 3(1)├ the person is unable to make a decision for himself or herself about the matter...because of an impairment of, or a disturbance in the functioning of, the mind or brain. So any impairment or disturbance, temporary or permanent, including: Dementia Learning disability Brain injury Mental health Personality disorder Physical health Alcohol and drugs	Decisions in relation to care, treatment and/or personal welfare	Routine	**Support principle** **Reasonable belief** the person lacks capacity and the intervention proposed is in their **Best interests** **Second opinion** (ECT)
		Serious (major surgery; serious pain, distress, impact and/or consequences)	And **Formal assessment of capacity** **Nominated person** **Second opinion** (best interests finely balanced)
		Authorised (treatment with serious consequences where the nominated person objects, deprivation of liberty, attendance requirement, community residence requirement)	And **Independent advocate** **Report including Medical Recommendation** **Trust Authorisation**
			Review Tribunal
			Public Guardian, High Court

Support principle
Mental Capacity Act (NI) 2016

* The Act introduces a new 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"

How did we do the research?

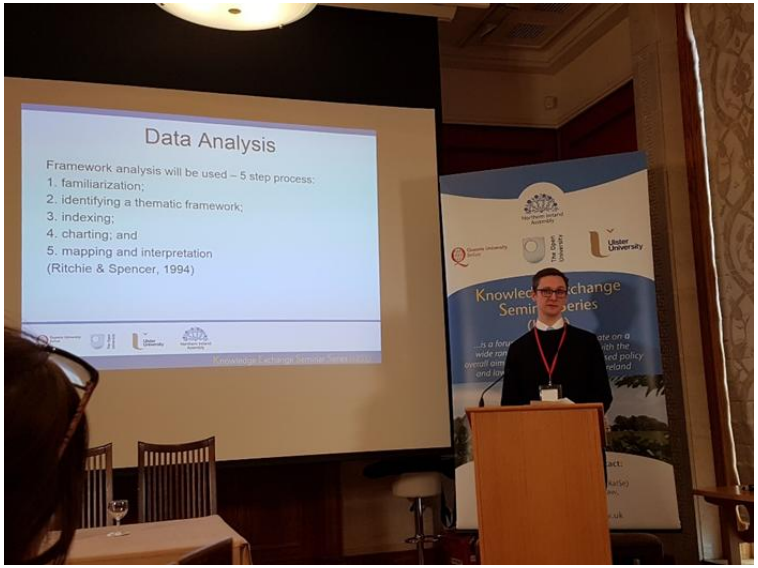
- **Peer researchers** interviewed 41 people with mental ill health and/or learning disabilities
- They asked lots of questions about:

  - People's experiences of decision making

  - What types of support people have had when making decisions

  - What people liked or disliked about the support they have received

Peer researcher process



What did we find out from the research?

Everyone has different experiences of decision making.

* Some people said in the past they weren't allowed to make decisions.

- Some people said they make their own decisions all the time.
- Some people said they find it hard to make decisions on their own.
- Some people said they put off making decisions because they find it hard.

Findings: Feelings about making decisions

Everyone has different feelings about making decisions.

- Some people said making decisions makes them feel scared.
- Some people find it hard to tell others when they are struggling to make a decision.
- Some people get confused if they have to make a decision quickly.
- Some people get confused if information is presented in a different way than they are used to.

Findings: How participants feel about support

Everyone has different feelings about support when making decisions.

- Some people said they feel angry when other people make decisions for them.
- Some people said that they liked someone helping them make decisions.
- Some people said that they sometimes liked help to make decisions, depending on what happened after the decision was made.
- Some people said they like having family support, and there needs to be more of this

Supporters

* Who provides support?

* Qualities of a good supporter
- approachable;
- good relationship;
- someone to talk to; good listener;
- empathy & understanding;
- kind, caring;
- good communication skills;
- advice/information;
- experienced/qualified/knowledgeable;
- trustworthy, respectful and shows interest.

Findings:
Types of Support

There are lots of different types of support people want when making decisions.

Some participants said they wanted:

- More information
- Accessible information (e.g. Easy Read)
- Someone to talk to
- More time
- Set options to choose from

Discussion

Participants said there were three things that make decision making harder:

- the type of decision to be made
- other people (the impact of the decision on them, and/or their influence)
- what might happen after the decision is made

We learnt that other people's roles in decision making are important

We also learnt that helpful support includes practical and emotional support

Recommendations

* Support for decision making needs to be individualised and the support principle should be understood in a broad and flexible sense to reflect this variation and complexity
* There was very little mention of existing, more formal processes of support such as advance decisions, crisis care planning and Enduring Power of Attorney
* The new Act will introduce a positive, more comprehensive framework for these more formal processes but considerable efforts may be needed to promote public awareness and understanding of what these involve

Recommendations

* Time was consistently identified as an important factor and it should be emphasised that if there is urgency to make a decision, what the cause of the urgency is and whether more time could be available
* There are already a number of excellent sources for guidance for supported decision making, as highlighted in this report, and these international exemplars should help inform the operationalisation of the support principle

Recommendations

* Although much of this project focused on the positive potential of support, the limitations and potential complexities of support should also be explicitly considered in the Code of Practice
* It should also be highlighted that what is intended to be support may, at times, move into undue influence, coercion and/or abuse
* Participants highlighted that they bring considerable experience of support and were open to being further involved in discussing these issues

Next steps

* Public consultation on Code of Practice
* Possible training intervention on Supported Decision Making
* Key role for social work – the new statutory duty reinforces what is already good practice
* Need for evidence on what support works for whom in what circumstances
* Peer researchers – social enterprise?