

# 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

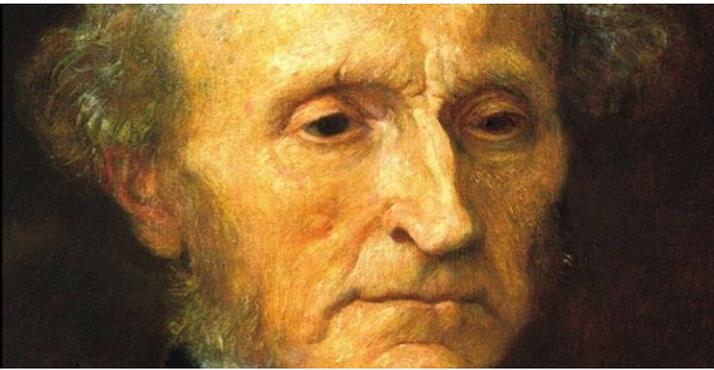


# International Advisory Group

- \* 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 – Bournemouth - 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
<p>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.</p> <p>So any impairment or disturbance, temporary or permanent, including:</p> <p>Dementia Learning disability Brain injury Mental health Personality disorder Physical health Alcohol and drugs</p>	<p>Decisions in relation to care, treatment and/or personal welfare</p>	Routine	<p><b>Support principle</b>  <b>Reasonable belief</b> the person lacks capacity and the intervention proposed is in their <b>Best interests</b>  <b>Second opinion</b> (ECT)</p>
		Serious (major surgery; serious pain, distress, impact and/or consequences)	<p>And  <b>Formal assessment of capacity</b>  <b>Nominated person</b>  <b>Second opinion</b> (best interests finely balanced)</p>
		Authorised (treatment with serious consequences where the nominated person objects, deprivation of liberty, attendance requirement, community residence requirement)	<p>And  <b>Independent advocate</b>  <b>Report including Medical Recommendation</b>  <b>Trust Authorisation</b></p>
			<p><b>Review Tribunal</b></p>
			<p><b>Public Guardian, High Court</b></p>



# Support principle

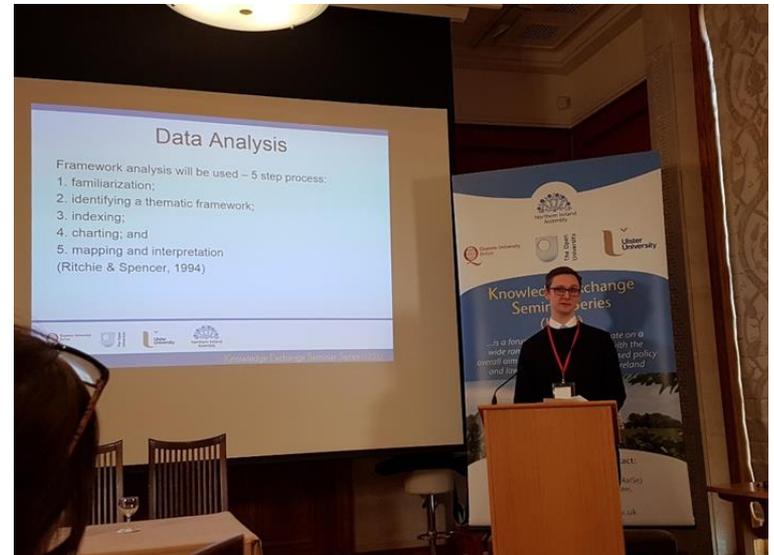
## Mental Capacity Act (NI) 2016

- \* 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?