



‘Decision-making processes in Learning Disability Services: in whose Best Interests?’



Danielle McIlroy
Lecturer in Social Work
Queen's University, Belfast
Co-Authors: Dr Lorna Montgomery
and Professor Gavin Davidson

Objectives

The presentation will address the following:

- Background for Research Study
- Definition of a Learning Disability
- Legislation
- Best Interests
- Research Methods
- Key Research Findings
- How do we determine what is an individual's best interests?
- Recommendations
- Questions
- References

Background for Research Study

- In recent years, the subject of determining an individual's capacity and decision-making ability has been one of extensive discussion and contention in the UK, Ireland and globally.
- The research study aimed to examine decision-making processes in learning disability services for individuals who lack capacity and to explore the Best Interests Principle as defined within the Mental Capacity Act (Northern Ireland) 2016.
- This research aimed to identify issues in current Best Interests practice in Learning Disability Services in Northern Ireland and consider recommendations on how this could be implemented for future practice.

Learning Disability Definition

The term 'learning disability' is a widely used and accepted term in the UK (NICE, 2014).

According to the Department of Health (2001:14), a learning disability includes the presence of;

A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) with;

- A reduced ability to cope independently (impaired functioning)
- Which started before adulthood, with a lasting effect on development.

How many people have a Learning Disability in Northern Ireland?

There are approximately 31,000 adults with a learning disability in Northern Ireland (Mencap, 2021). Of these adults, 24,000 are of working age (between 18 and 64 years old).

There are approximately 11,000 children with a learning disability in Northern Ireland (Mencap, 2021).

Legislation

In Northern Ireland there are two key pieces of legislation that are used when there are concerns regarding an individual's ability to make decisions in their best interests;

- Mental Health (Northern Ireland) Order 1986
- Mental Capacity Act (Northern Ireland) 2016 - Currently only partially implemented.

Other relevant legislation;

- Human Rights Act 1998
- Health and Personal Social Services (Northern Ireland) Order 1972
- Children (Northern Ireland) Order 1995

New Legislation, New Opportunity

There are a group of participants who were permitted to participate in the interviews, however, they did not have capacity to consent to participate in the research.

This gives an individual who lacks capacity to consent to the research and has experienced the Best Interests process, the opportunity to participate in the research. This is possible if the individual is able to communicate with the researcher about their experiences, without becoming distressed and all appropriate safeguards have been met.

This is a significant progression in research and legislation. With the implementation of the MCA (NI) 2016 Safeguards, many individuals will have the opportunity to share their stories and have their voices heard by researchers, who previously were excluded from many research studies.

The Mental Capacity Act (Northern Ireland) 2016 Money and Valuables & Research Code of Practice details the inclusion criteria of participants for research in Chapter 3.5.



Best Interests

The research involved interviewing individuals with a learning disability who have experienced Best Interests processes and surveying professionals about their experiences of these processes.

For those using and working in learning disability services, the traditional approach has been that the decision should be made in the individual's Best Interests. However, now with the implementation of the MCA (NI) 2016, Best Interests is enshrined in legislation and must be applied to any proposed Deprivation of Liberty before the act can lawfully proceed.

Although the MCA (NI) 2016 is indicative of a substitute-decision making regime, with the inclusion of the support principle suggests that it is being underpinned by a supported-decision making model. The MCA (NI) 2016 Code of Practice suggests that *“Proper and full consideration of best interests guarantees that the individual's rights, will and preferences are respected in line with obligations set out under The UN Convention on the Rights of Persons with Disabilities”*.

Research Methods

Mixed Methods Study

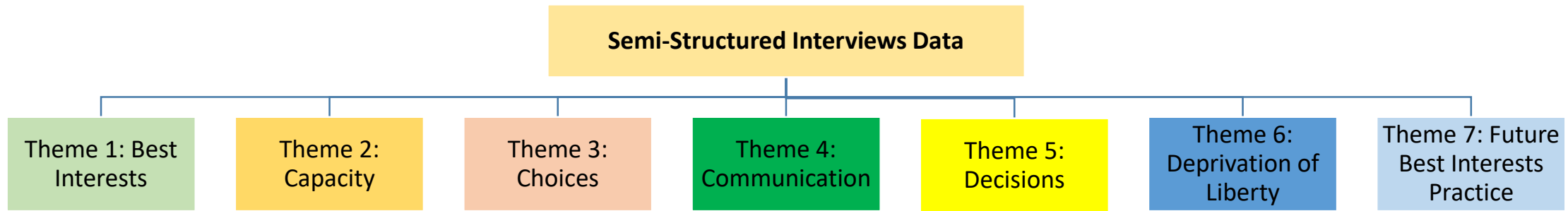
Semi- Structured Qualitative Interviews

- 14 Participants
- Known to Statutory Learning Disability Services
- 3 participants were not able to provide consent for research and their Personal Consultee was consulted.

Electronic Surveys (Qualitative and Quantitative)

- 28 Participants including Social Workers, Learning Disability Nurses and Medics.
- All participants were employed to work with individuals with a Learning Disability within statutory services.

Semi-Structured Interviews analysed using Thematic Analysis



Professional Surveys

Surveys were distributed electronically to professionals from two HSCTs who were working with individuals with a Learning Disability.

28 Professionals completed the surveys. Of the 28 who completed the surveys there were;

-21 Social Workers

-3 LD Nurses

-1 OT

-1 Consultant Psychiatrist

-2 GPs

Those participants had a range of years working in Learning Disability services, from less than one year to 30 years.

The participants' experience in completing Best Interests decisions both prior to and following the implementation of the MCA (NI) 2016 varied from no experience to those who had been involved in ten or more Best Interests decisions.

Key Findings

Choice

- Both interview and survey responses highlighted how there was limited availability of options to choose from in relation to day opportunities and accommodation. The research highlighted that a number of participants reported only being offered one option or offering one option.
- A number of interview participants reported that they did not choose where they lived or what they did during the day. They reported that where they lived or what they did during the day was decided upon by someone else.

Interviewer: *“Do you feel it was your choice to come here (supported living accommodation) or was it somebody else’s choice?”*

Participant: *“Nah, well, it was my foster mum’s choice because she thought it would be better if I was with someone younger and with more girls instead of just anyone way over my age and get rid of embarrassment and stuff.”*

- Consideration about how choice is perceived by some of the interview participants. How can someone make a choice if they do not know what the options are.

Key Findings

Involvement in Best Interests Decisions

- Some survey participants detailed how they involved the individual in the Best Interests decision including; consulting with the individuals, their Nominated Person and their family.
- However, survey participants also reported that there should be further inclusion of individuals and their families in Best Interests decisions.
- Interview participants reported that those making the Best Interests decision should know the person before a decision was made and consider risk of harm as a reason for making a decision on someone's behalf.

Key Findings

How Best Interests Decisions are determined

- There are occasions when Best Interests decision meetings are held and occasions when they are not. It is not clear why some individuals may have a Best Interests meeting and another does not.
- Some responses highlighted the inclusion of the individual in the Best Interests decision and others indicated that they were not.
- Not all responses detailed the inclusion of the Nominated Person and family in Best Interests decisions.

Key Findings

Special Regard

- The interviews explored participants' perspectives on Special Regard in relation to the Best Interests decision. The research team acknowledged Special Regard is a complex term to understand. Some interview participants indicated their thoughts on how Special Regard was or was not considered in their Best Interests decisions.
- Some survey participants suggested that an individual's Special Regard was unable to be obtained due to their 'severe learning disability' diagnosis.
- One social worker participant reported their reflections on Special Regard;

"It caused me to reflect on how the individual had been attending services for over 15 years without anyone trying to establish their wishes and feelings on this. They had never been asked before."

- There is learning for those making Best Interests determination statements in relation to how they can best capture the individual's wishes, feelings, beliefs and values in respect of future care and treatment.
- The findings reported that some survey participants informed the individual of the Best Interests decision following completing the capacity assessment. It is important that there is a clear differentiation between the Capacity Assessment and the Best Interests Determination Statement.

Key Findings

Communication

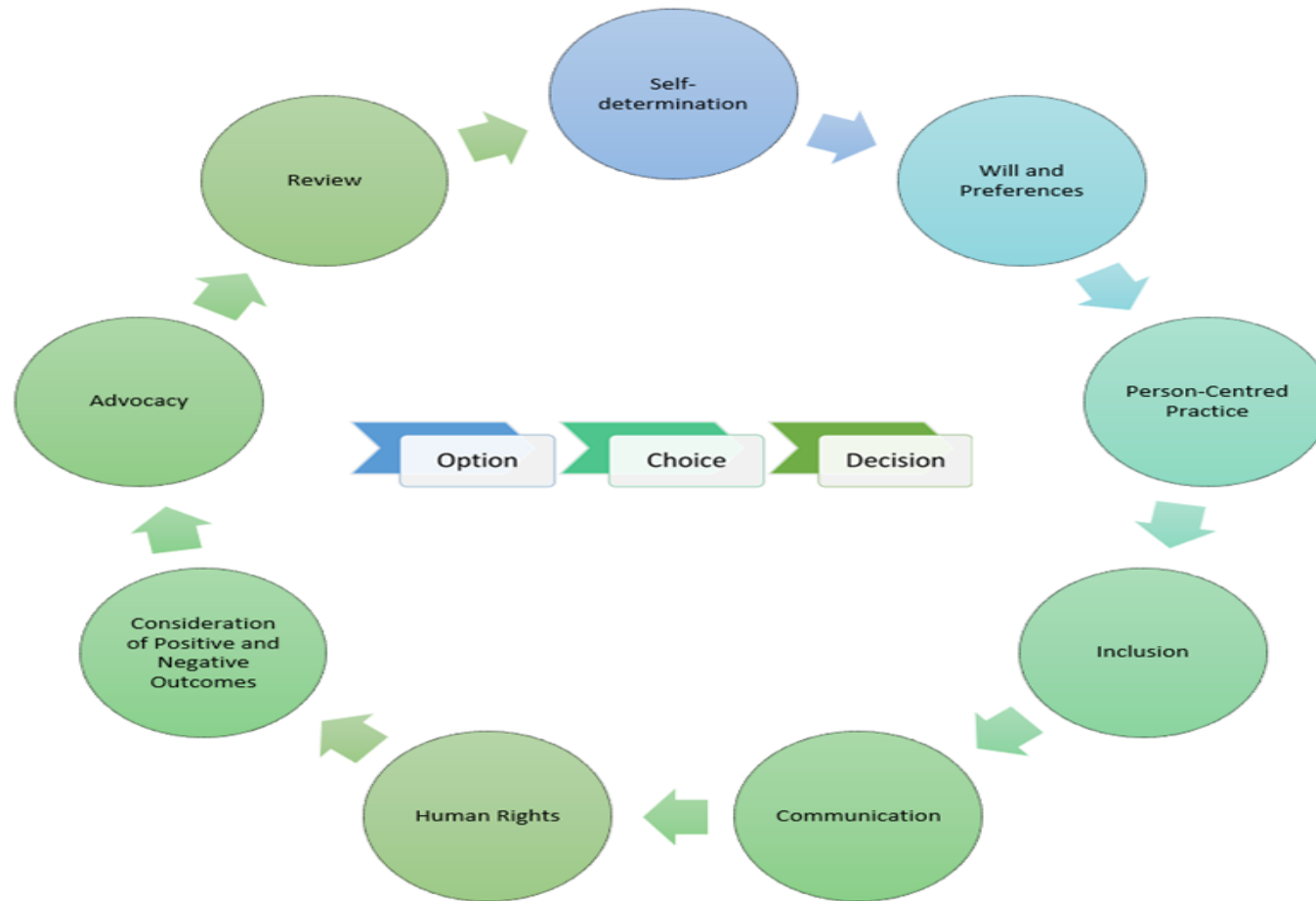
- The interview findings highlighted the language we use, including professional jargon.
- An increased need to support an individual to meet their communication needs. Over half of survey participants indicated that they referred to Speech and Language Therapy for communication support during the Best Interests Decision-making process.
- Consider how we communicate options / choices / decisions / outcomes to individuals.
- We need to consider what is not communicated by the individual and why?

So how do we determine what is in an individual's Best Interests?

- Involve the individual from the beginning of the decision-making process to the end.
- Consider the support the individual needs, including the supports they may need before being involved in the decision and those supports after, particularly if the decision is not what they had hoped.
- Communication
- Options / Choice / Decision – Three Stage Model of Decision-Making
- Special Regard for the individual's wishes, feelings, beliefs and values
- Consult NP / family members / friends and others who know them well

Three Stage Model of Best Interests Decision-Making

Option-Choice-Decision



Take home message

Weaved throughout the findings is the message;

“No decision about me, without me”.

Secretary of State for Health (2010)

Recommendations

- Consideration of Best Interests Meetings and the development of a regional Best Interests Meeting framework. Additionally, the framework could adopt the Three-Stage-Model of Best Interests Decision-making. There is a possibility that these guidelines could be developed regionally and could apply to all programmes of care.
- Recording specific statistics on how many individuals from each programme of care are subject to a Deprivation of Liberty. This information could be used as evidence for funding and additional resources such as easy-read documentation and access to Speech and Language Therapy.
- Those who make Best Interests decisions should consider providing additional support to the individual following the outcome of the decision. This research has highlighted that not all individuals, who have had a Best Interests decision made on their behalf, were happy with the outcome of the decision.
- Develop technology as a tool for individuals to be further involved in the Best Interests decision-making process. For example, an electronic tablet.
- The development of further user-friendly documentation for delivering the outcome of the Best Interest decision to the individual and their Nominated Person. It may be useful to consider developing an easy-read version of legal forms to accompany the legal forms.
- Due to the changing cultural landscape in Northern Ireland, further translated or accessible information on MCA (NI) 2016, such as braille and other languages, should be available on MCA website.
- Additional public engagement forums may be used for individuals to learn more about the MCA (NI) 2016 and how to access support.



Questions?

Thank you



Email: danielle.mcilroy@qub.ac.uk

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