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A Qualitative Study Exploring Supported Decision-Making for persons with Intellectual Impairments: Article 12 of the UN CRPD

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Goal of the Presentation

My goal is to provide an overview of my PhD qualitative research project entitled “Supported Decision-Making for Persons with Intellectual Disabilities” and then for you (the target audience) to answer these questions:

(1) Did I make the right methodological choice in terms of balancing the feasibility and validity of this qualitative study? and

(2) To provide any further suggestions to this qualitative study?

Outline of Presentation

Empirical study
- What does Art. 12 require?
- Relevance of the study
- Objective and specific aims
- Method (observational & semi-structured Interviews)
- Study design, sample & setting
- Data collection
- Observations & Semi-structured interviews
- Summing Up
Background: Article 12 of the CRPD

Article 12(1)
• Addresses the right to make one’s own decisions (legal capacity) and recognises the personhood of persons with disabilities

Article 12(2)
• Persons with disabilities have same decision making autonomy as non-disabled

Article 12(3)
• Requires State Parties should take appropriate measures to support decision making

Article 12(4)
• Guarding against the abuse of such supportive decision making

Article 12(5)
• Provides legal measures to own property and have financial control and be able to take out bank loans and mortgages.

Background: What does Art.12.3 Require?

Substituted Decision-Making

Supported Decision-Making

Background: Relevance of the Empirical Study

- Use of substitute decision-making (e.g. guardianship) for persons with intellectual disabilities is coming under increasing criticism (Herr, 1989; Quinn, 2009) from the disability rights advocates urging to replace supported decision-making

- Growing interest in supported decision-making derived from Article 12 of the CRPD which is based on normative arguments on this model (Dhanda, 2007; Minkowitz, 2008; Kohn, 2012)

- Some attempts made to understand how supported decision-making processes operate in practice (Kohn 2012)

- No sufficient empirical evidence to know the extent to which supported decision-making arrangements can remedy the problems posed by substitute decision-making systems

- Lack of evidence as to how decisions are actually made in supported decision-making relationships
An Explorative Qualitative Study

The objective of this qualitative study is to investigate how health and social decisions are made by persons with mild to moderate intellectual disabilities and their support worker:

- To explore how much support is provided in the decision making process for persons with intellectual disabilities
- To explore opportunities how support can be provided, and
- To explore the role of the support worker in the supported decision-making role

Data Collection: Observations

From the observational data
1. Why the decision took place
2. How did the service users support decision-making in specific situations
3. When and why service users were excluded from decisions
4. What roles did the staff and supporters play in the decision-making process
5. What were the outcomes

Objective: extract insights from the data relevant to question

Development of a semi-structured questionnaire

Data Collection: Semi-structured interviews

Development of a semi-structured questionnaire will be based on the following decisions (health and social activities)
Summing Up the Empirical Study

Observations
Non-participatory

Semi-structured interview

Documentation

Thank you for your kind attention!

References


