

# Understanding the Lived Experience of Supported Decision-making

## Research Methodology Update, September 2013

### Introduction

People with disabilities are experts in their own experience, with stories to share on how to overcome challenges. A key goal of the project, *Understanding the Lived Experience of Supported Decision-making*, is to hear from people with disabilities about their own experiences. In order to include people with disabilities in our research in a manner that is ethical and empowering for participants, we have been reviewing methodology on involving people with disabilities in research. In this update we share our findings and sources. We welcome your input on methodology, and encourage you to share this update and related research within your communities in order to encourage open dialogue on inclusive research practices.

The underlying question here is—what research methods can best accommodate, include and empower people with disabilities? This update summarizes disability research ideals, realities and qualitative methodology. A list of relevant citations is also provided at the end of this summary.

A key issue is whether the research is *on* or *with* people with disabilities. *Participatory action research* is an approach that shows promise. It emphasizes the pursuit of practical solutions to issues of pressing concern for people with disabilities. This approach highlights social inequalities while aiding people with disabilities to identify and address a cause that is important to them.

A number of concerns have been raised regarding research involving people with disabilities. Research ideology emphasizes the importance of changing and removing the barriers people with disabilities face; however, research projects often do not empower the participants or result in positive impacts on their lives. Although the principles guiding disability research are conceptually well grounded, the principles are not necessarily realized in practical terms. Setting the criteria for research and obtaining consensus from the disability community is a difficult but important task. There is an inherent danger of priorities being lost in the focus on ideological questions. With the above concerns in mind, we set to investigate potential methodological approaches that can accommodate, empower and include people not only ranging in mental and physical abilities, but also from diverse backgrounds, including gender, ethnicity, class and sexualities.

### Qualitative Techniques

The most common methods for conducting research with individuals with cognitive challenges and disabilities include semi-structured interviews, photographic techniques

and proxy responses. Less popular methods include focus groups, questionnaires and surveys. Most researchers favour adopting a mixed methods approach.

People with learning disabilities need to believe that their views are valid and important in order to feel the research process is relevant and worthwhile. Semi-structured interviews provide the opportunity to develop a relationship with the participant and assure them that they will be listened to and understood. This requires sensitivity from the interviewer. It can also be helpful to invite the participant to include a familiar, supportive person in the interview process. This process also provides an opportunity for the researcher to get to know the participant better and thereby become better able to adapt processes to suite the unique needs and capabilities of each participant.

A powerful approach to help develop trust and respect is to check back in a process of participant validation. This “checking back” stage becomes even more important when the individual’s communication difficulties may pose barriers to understanding what the participant is trying to communicate with words.

For individuals with profound learning or communication difficulties, the whole interview may rely on interpretation by a representative. Often this person is a caregiver or relative who is emotionally connected to the person with a disability who is being interviewed. The support person can act as a proxy, answering questions as if they were the other person. Offering additional emotional support of a familiar, valued person involved in the interview process can provide comfort to a participant that helps empower them to express their views.

## **Conclusion**

It is likely that the most appropriate mix of methods will depend on the time, budget and focus of the research to be conducted. Flexibility is key. What does it mean to utilize an approach that accommodates, includes and empowers people with disabilities? We will emphasize an approach that:

- Focuses on the unique strengths, qualities and abilities of each participant and her support networks;
- Allows each interview participant to be involved to the degree that she or he feels comfortable;
- Incorporates strategies for checking to make sure we have understood and not misrepresented what interview participants have shared;
- Supports participants to include in the process friends or family that help them communicate or feel safe; and
- Shares the results of our research with all stakeholders.

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