Constructing Disability: Exploring Conceptualization of Intellectual Disability among Researchers through Participatory Research

Rebecca Monteleone, School for the Future of Innovation in Society
Alliance for Person-Centered Accessible Technologies, NSF IGERT Fellow

Introduction

- As the field of medical genetics innovates at a breathless speed, ethical questions around research impacting individuals with disabilities are becoming increasingly important.

- Research around genetic testing and engineering is emerging as particularly vulnerable to scrutiny from the disability rights community, as it is perceived as a form of eugenics that seeks to alter or eliminate individuals with disabilities.

- This project intends to explore the way in which intellectual disability (ID) is constructed among advocates with ID and researchers engaged in these fields, and explore potential protocols for collaborative dialoguing as part of the research process.

Significance and Purpose

- Disability rights activists and bioethics organizations have recently raised concerns around the discriminatory practices linked to prenatal testing (McCabe & McCabe, 2011), and the threat that genetic engineering poses to several disability communities and cultures.

- Scholars suggest that people who occupy traditionally oppressed social roles (such as people with disabilities) have knowledge about their positions that is not available to people in privileged positions (Harding, 1991).

- By confronting and making explicit any discrepancies in the construction of disability, this work will impact directions and goals of future innovation through increased person-centeredness and sensitivity to disabled identities and communities.

- This work will utilize a co-researcher with an intellectual disability during development, data collection, and analysis phases. Through incorporation of such a co-researcher, it seeks to carve out a space for individuals with ID to become engaged more fully in research processes.

Anticipated Flow of Study
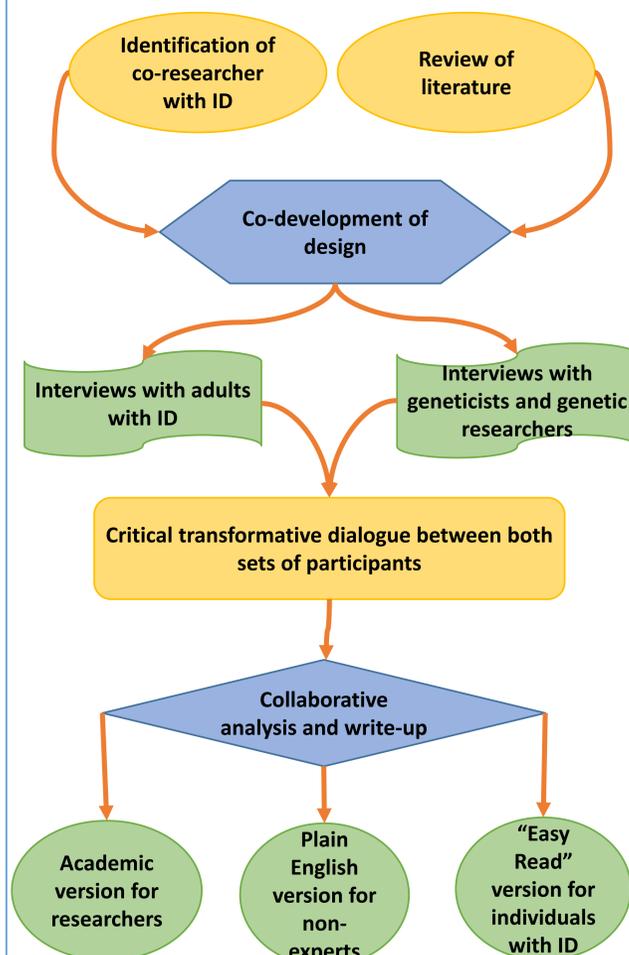
Research Questions

1. How do scientists engaged in medical genetic research and related fields develop their framework for understanding intellectual disability (ID) and what impact does this construction have on their work?

2. How does this understanding differ from the manner in which adults with ID conceptualize disability?

3. What effect does dialogue between these two groups have on both sets' construction of disability and future directions for research?

Context and Foundational Theory

- Oliver (1992) suggests that traditional research is disempowering and disenfranchising for people with disabilities because it divorces the knowledge from the participant and allows people without disabilities to make decisions on their behalf.

- Emancipatory and empowering research methods, including participatory research, are seen as a challenge to traditional power-relations in research methodologies (Kitchin, 2001).

- Standpoint theory suggests that knowledge is crucially linked to one's social position (Harding, 1991), and science is not and cannot be inherently objective. Incorporating people with disabilities in the research process would therefore introduce new knowledge stemming from experience.

- Opinions and attitudes are interactional – not something that can be garnered in isolation (Billig, 1996). Dialoguing between these groups is therefore a valuable methodology to implement when exploring transformation of attitudes.

Current Status

- Previous work has developed a framework for understanding the components considered in disability construction for adults with intellectual disabilities (Monteleone & Forrester-Jones, 2016).
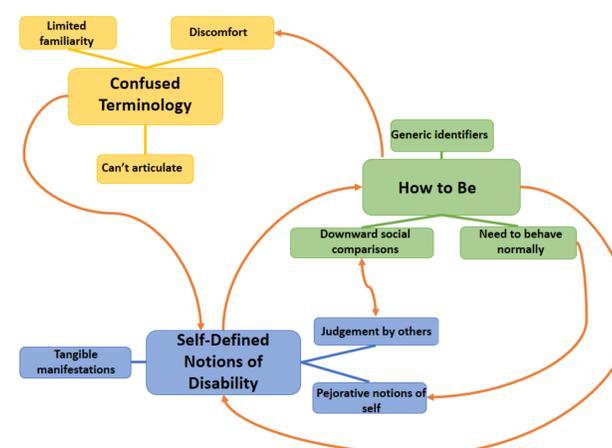
A model of disability conceptualisation in adults with intellectual disabilities (Monteleone & Forrester-Jones, 2016)

Anticipated Methods

- Participatory Research – collective development, execution, and analysis. It entails active engagement of traditionally marginalized and disenfranchised populations in order to transform research into a more socially just practice (McGuire, 1987).

- Interpretive Phenomenological Analysis (IPA) – qualitative analytical framework that is inductive in nature and seeks to understand participants' thoughts, ideas, and interpretation of experiences (Smith, Flower & Larkin, 2009).

- Critical Transformative Dialogues – Emerging from critical social science, this design seeks to "design, interpret, and then critique", in conjunction with participants, the status quo of a chosen system, and develop emancipatory alternatives (Trede, Higgs & Rothwell, 2009). Participants with intellectual disabilities and researchers doing work around medical genetics will engage in these dialogues together.

- Diverse Dissemination – It is the intention to create several different versions of the finalized analysis, including an academic version for researchers, a plain English version (7th-8th grade reading level) for non-experts such as practitioners, policy-makers, and advocates, and an "Easy Read" or "Words and Symbols" version for individuals with intellectual disabilities. Extensive dissemination is intended to increase dialogue and transformation within fields relating to individuals with ID.

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