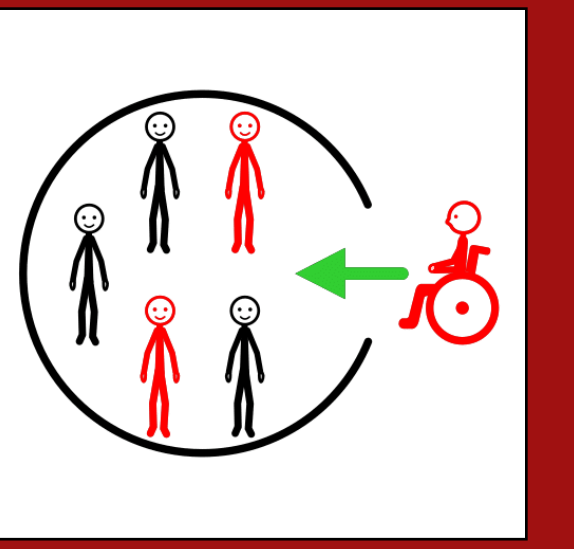


Towards Acknowledging Dignity through Research Participation



Negotiating Vulnerability across Dis/Abilities and Institutional Barriers

Applying the Capabilities Approach to the Research Process

Martha Nussbaum frames the key question concerning human dignity and capabilities as “What is each person able to do and to be?” (Nussbaum, 2011, p. 18). This conceptualisation of dignity underlying the Capability Approach (CA), can be applied to research processes and designs, too. CA can be used as a tool (see Robeyns, 2005) to guide decisionmaking in designing research projects on a very fundamental level – starting with research participation: Who is able to participate in what kind of research and in what kind of way?

Researching with Children of all Dis/Abilities including Complex Disabilities

Although their right to have their views heard and listened to and to be involved in decisions affecting their lives (UN-CRC, 1989), children’s voices and perspectives are still often neglected in research. This holds particularly true for Disabled children and youth (Young & Clerke, 2024) and is aggravating even more in the context of Complex Disabilities (CD) (de Haas et al., 2022; Grace et al., 2024). Persons with CD – often referred to under the label of Profound Intellectual and Multiple Disabilities (PIMD) as well – have historically been construed and constructed as the epitome of a ‘vulnerable population’ (Kittay, 2005; Vehmas & Mietola, 2021). Researchers often struggle to find ways to facilitate participation in research for a group of people whose lived experience diverges drastically from implicit and explicit norms (Maes et al., 2021; Skarsaune, 2023) and who challenges notions of administrative bodies of what constitutes a capable research participant (see Mietola et al., 2017).

Institutional Barriers to Researching in Contexts of Vulnerability

Drawing on Nussbaum and the CA to question who is able to be (considered) a research participant and who is excluded from the generation of knowledge identifies structural institutional barriers. Based on experiences from a qualitative research project exploring experiences of students with Additional Health Care Needs wanting to include children with Complex Disabilities as highly relevant stakeholders, there were several challenges to formal approval procedures. The graphic outlines institutional barriers to participation of groups perceived as highly vulnerable based on the example of CD: Identified barriers to participation are...

