

Disability representation and research leadership: Tensions and solutions

- Melanie Hecker, Research & Training Consultant
- Jessica Kramer, Associate Professor, University of Florida

Outline

- Defining our concepts (10 minutes: Jessica)
- Example tensions (10 minutes: Melanie)
- Discussion of solutions (15 minutes: Melanie, Jessica, and attendees)

The ethics of representation

- Representation: How findings, participants, and communities are represented in community-based participatory research
 - Decisions about what is presented about the community and its members
 - How data are interpreted,
 - How participants/community voice is represented
 - Where the findings are disseminated

(Banks et al., 2013; Brugge & Kole, 2003; Ellis, 2007; O'Sullivan et al., 2023; Pickering & Kara, 2017)

The ethics of representation

“Community” as a physical space



shutterstock.com - 61425274



<https://www.tillinc.org/services/residential-services>

“Community” as common characteristics or identities



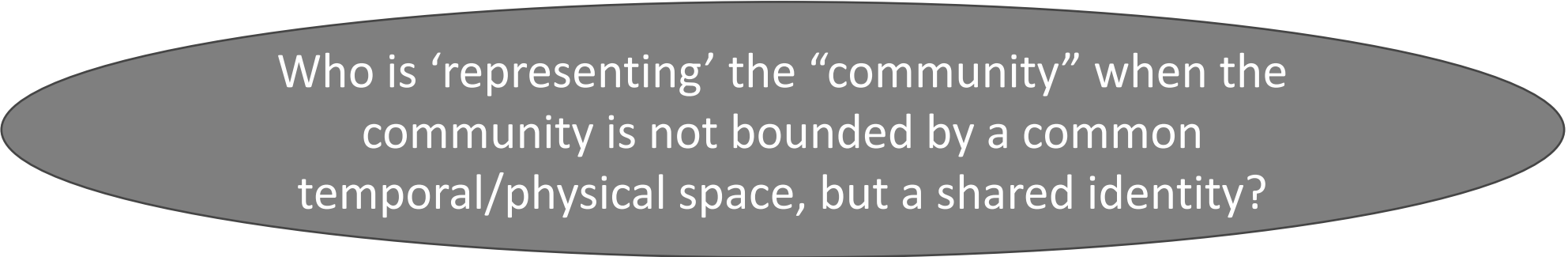
<https://disabilityfoundation.org/who-me-self-esteem-for-people-with-disabilities/>



<https://www.istockphoto.com/photo/portrait-of-a-woman-in-a-wheelchair-gm1348146298-425441731>

Additional ethics of representation

- One additional point for consideration in inclusive/collaborative research:



Who is 'representing' the "community" when the community is not bounded by a common temporal/physical space, but a shared identity?

- We must consider:
 - *How are individuals identified and selected for inclusive research leadership roles?*
 - *What experiences are they intended to 'represent'?*
 - *What boundaries are recognized in their experiences?*

What is representation?



Created by georgi
from Noun Project

Representation is....

- Using one's experiences to influence opinion or action
- Exemplification: To be an instance of, to serve as an example (Merriam-Webster)
- To show or illustrate a point through one's unique lived experience



Created by Meko
from Noun Project

Representation is not...

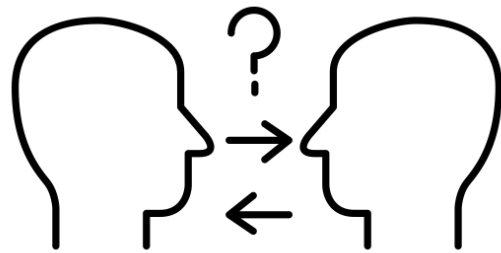
- One person standing for another
- One person's experiences representing all experiences (or "typical" experience)

Lived Experience on Collaborative Research Teams

- Lived experience
 - Personal knowledge about the world gained through direct, first-hand involvement in everyday events rather than through representations constructed by other people¹
 - We all have lived experience (Goode, personal communication)
- Our collaborative teams often include people with a range of experiences including:
 - A family member
 - A person receiving services
 - A clinician

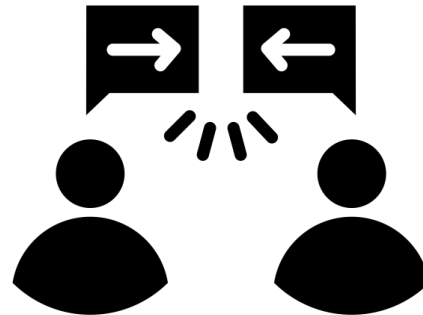
¹This definition of lived experience appears throughout those cited on web-based platforms but it is not attributed to a specific author. The following is one such citation. McIntosh, I. & Wright, S. (2019). Exploring what the Notion of 'Lived Experience' Offers for Social Policy Analysis. *Journal of Social Policy*, 48(3), 449-467. doi:10.1017/S0047279418000570

Tensions in Representation



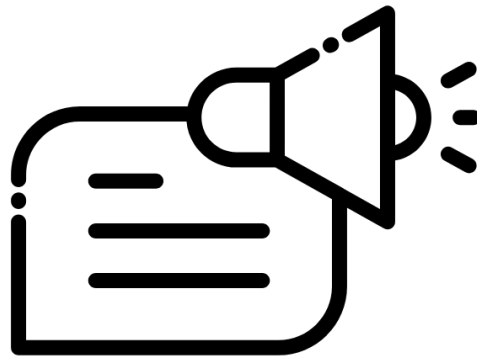
Conflicting Access Needs

- Accommodation:
 - Alteration of environment, curriculum format, or equipment that allows an individual with a disability to gain access to content and/or complete assigned tasks.
- We strive to provide access for all, yet one person's accommodation may become an access barrier for another person



Speaking “for the community”

- An individual’s lived experience or advocacy role within a very specific group/community is presented as representing all experiences
- It may be simpler to consider the primary/predominant perspective, yet all experiences are valid, including those who may differ or be in the minority.

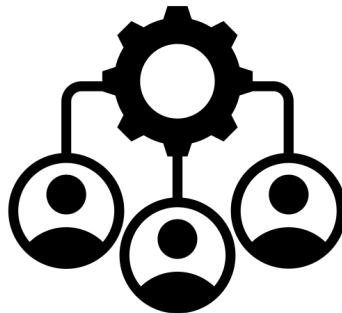


Disability Nomenclature

- The power and control inherent in words and labels assigned to classes of people can make nomenclature very important
 - Person with disability/ Disabled Person
 - Person with special needs/Ability
 - Intellectual Disability/ Learning Disabled
- May differ based on other identity factors, such as level of education, race/ethnicity, nation, or role in the community (parent vs. self-advocate)

Sub-coalition Conflicts

- The broader the conceptual community (e.g., people with developmental disabilities and mental health service experiences) the more subgroups there are within the community
- Subcoalitions may have strong differences in the value, need or importance of a specific topic or issue



Discussion: Potential Solutions

Tension	Potential Solution
Conflicting access needs	Discuss joint compromise Involve all parties in generating solutions/alternatives Flexibility & time ASAN Protocol
Speaking “for the community”	Before you start substantial work, point out potential ideological differences Avoid having only 1 person intended to represent an entire experience
Disability Nomenclature	Ask each individual what term they prefer Openly acknowledge differences in nomenclature and explain the team’s decision to use specific terms Focus on shared values for the content of the message
Sub-coalition Conflicts	Hold discussion on differences between norms or values Communicate positions clearly, calmly and in a non-judgemental way

References

- Banks, S., A. Armstrong, K. Carter, H. Graham, P. Hayward, A. Henry, T. Holland, et al. 2013. “Everyday Ethics in Community-Based Participatory Research.” *Contemporary Social Science* [8](#) ([3](#)): 263–277. doi:10.1080/21582041.2013.769618
- Brugge, D., and A. Kole. 2003. “A Case Study of Community-Based Participatory Research Ethics: The Healthy Public Housing Initiative.” *Science and Engineering Ethics* [9](#): 485–501. doi:10.1007/s11948-003-0046-5.
- Ellis, C. 2007. “Telling Secrets, Revealing Lives: Relational Ethics in Research with Intimate Others.” *Qualitative Inquiry* [13](#) ([3](#)): 3–29. doi:10.1177/1077800406294947
- O’Sullivan, S., Desmond, E., & Buckley, M. (2023). The Ethics of Engagement and Representation in Community-based Participatory Research. *Ethics and Social Welfare*, *17*(2), 159–174. <https://doi.org/10.1080/17496535.2023.2211756>
- Pickering, L. and Kara, H. 2017. “Presenting and Representing Others: Towards an Ethics of engagement.” *International Journal of Social Research Methodology*, [20](#)([3](#)): 299–309. doi:10.1080/13645579.2017.1287875