

Every voice matters: Promoting inclusion of people with disabilities in qualitative research methods

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Methodological brief

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People with disabilities might face barriers to inclusion in these areas ...



- / **Attitudinal barriers and reliance on proxies**
- / **Communication and physical access barriers**
- / **Lack of awareness of reasonable accommodations**



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Facilitators to inclusion at all phases

- / **Use of inclusive language**
- / **Study design**
- / **Design of moderator or interview guides**
- / **Data collection**



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Facilitating inclusion: Language matters!

- / **Person-first language**
 - Person with a disability
 - Wheelchair user
 - Person with a mobility or vision impairment
- / **Sets the tone across all aspects of the work**
 - Proposal or research plan
 - Institutional review board application
 - Participant screener form and consent form
 - Interview guide
 - Study findings, description of group participants



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Facilitating inclusion: Recruitment and screening

/ **Set the stage for all potential participants to make informed decisions about participation**

- Purpose and topics planned
- When and where group takes place
- What participation entails (group setting and verbal participation)

/ **Include questions to inform**

- Understanding of expectations for the group
- Whether and what kinds of accommodations might be needed

/ **Use of proxies versus self reporting**



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Facilitating inclusion: Design of interview guide

/ **Minimize cognitive burden in questions, probes**

- Use plain language
- Keep sentence structures simple

/ **Duration and size of groups**

- Insert intentional break
- Smaller group sizes where needed

/ **Co-creation and use of advisory panels**

- Direct input from people with disabilities



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Facilitating inclusion during data collection - 1

/ **Value of setting expectations at outset of group**

- Agreement to respecting all group members
- Logistics of speaking in the group

/ **Providing reasonable accommodations**

- For people who are deaf or have hearing impairments
- Completion of consent forms

/ **Physical space considerations**

- Space at the table for wheelchair users
- Presence of personal care attendants in the room (or not)



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Facilitating inclusion during data collection - 2

/ **Moderators demonstrating respect for all participants**

- Pacing, tone, and volume of moderator speech
- Always ask - never assume support is needed
- Respectful listening for people with speech impairments

/ **Co-facilitation of group with person who has lived experience**

- Advantages
- Challenges



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Final thoughts

- / **Diversity of voices at the table promotes equity**
 - Inclusive practices and design facilitate opportunities to capture diverse experiences
 - Our data are richer for it
- / **We all have a role in making inclusion of people with disabilities the norm**



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Mathematica
Progress Together

<https://mathematica.org/focus-areas/health/disability>



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Additional resources

- / Crocker, A.F., and S.N. Smith. "Person-First Language: Are We Practicing What We Preach?" *Journal of Multidisciplinary Healthcare*, vol. 12, 2019, pp. 125–129. doi:10.2147/JMDH.S140067.
- / Haelle, T. "Identity-First vs. Person-First Language Is An Important Distinction." 2019. Association of Healthcare Journalists. Available at <https://healthjournalism.org/blog/2019/07/identity-first-vs-person-first-language-is-an-important-distinction/>.
- / Hensler-Cullen, J.A. "Disability Etiquette." Webinar. December 16, 2014. Available at www.respectability.org/2014/12/disability-etiquette/. Accessed April 15, 2022.
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