

Practical guides for participatory methods

Disability inclusive research

What is it and how can we do it?

Introduction

In the past, people with disabilities have been left out of many aspects of life including research. They have not usually been included in 'mainstream' studies about key topics such as health, education, WASH, gender empowerment, social and political participation, while other groups in populations are more routinely asked for their views and their qualitative data is collected. It is often perceived to be too difficult or expensive to include disabled people. This is discriminatory and leads to continued lack of understanding about their lives. We need to collect disability-inclusive data to understand disabled people's situations and needs, alongside others' views.

Additionally, disability-specific research has been rare and poorly funded. Now, partly in response to the game-changing UN Convention on the Rights of Persons with Disability (UNCRPD, 2007), the rights of disabled people to participate in all aspects of life are recognised, and research priorities are changing to include disability data and disabled people's perspectives on many topics.

Globally there are approximately 1 billion + people with disabilities, equivalent to 15+% of any population (about 1 in 7 people). Rates increase with age, around 10% of children have disabilities, whereas in elderly populations the figure rises to 40% or more (WHO and World Bank, 2011). Ideally, you should aim for these percentages to be represented in your research populations, as well as aiming for gender equality, as women and girls with disabilities are more excluded than boys and men. It is also good to remember that people with impairments have other identities apart from perhaps identifying as disabled. They may see their other identities, such as being a teenager, a parent, being a head of a household, being gay, or being a community leader as more important than being seen as disabled.



Impairment and disability

Social and human rights models of disability place emphasis on the way society generates negative attitudes to people who have some kind of difference. Disability is the outcome of negative perceptions, and is separate from impairment, which is the way that an individual is different from others. Someone may experience practical consequences of these differences, others not so much. Other people's responses often become barriers to their participation and inclusion. The 5 broad categories of impairment are: Physical, Visual, Communication/Deafness, Cognitive and Social-Emotional.

Some people have combinations of these and everyone's situation is different. Some people are born with an impairment, others acquire it during life because of an illness or accident. People have different medical causes of their difficulties, but these details are less important than what specific help they need to join in with everyone else. You do not need to ask people about these details and it can be intrusive to do so.



How to be disability inclusive: Some general tips

- First and most importantly, ask people what they need in advance and during events— don't guess or assume what is needed. People can usually tell you very clearly. Don't help people without checking with them what is needed.
- Don't be afraid to include and invite people to join your event or research. Remember people with disabilities are more like everyone else than they are different. Be open and accepting of people's differences. Value their contribution and participation.
- Include a line in your research budget to cover the cost of 'reasonable accommodation' – this could cover the cost of things like sign language interpreters, an assistant attending with someone, or producing accessible materials such as braille or digitally accessible formats.
- Think about different types of barriers which could prevent participation, these might be physical, communicative, attitudinal or structural. Some are almost invisible and difficult to spot!
- When planning participatory activities, think carefully about how everyone will be able to join in. You may need to make different adjustments for different people during different activities.
- Make sure your ethics statements include consideration of the potential extra risks to people with disabilities and say how these will be mitigated. For example, be careful about anonymity as some people may be easily identified by their impairment and or other characteristics. You need to make sure that disabled people are not subtly bullied or coerced into joining with something they don't really want to do. People may not be used to being asked for their opinions or having a choice. Often in practice, you need to be flexible and stick to the principles of ethics, but perhaps adapt your practice to suit a specific situation.
- Most participatory and action orientated research activities and methods can usually be adapted for people with specific access needs. For example people with visual impairment can join in with visual activities such as drawing (eg river of life) or photovoice, deaf people can enjoy storytelling, music and dance, people with physical impairments can do sports etc. Don't assume something can't be done, check with the person.
- Make sure that people can position themselves in the room in order to see or hear well.



Practical steps for different stages of the research process

a. Planning

- Ask people what support needs they have, in advance if possible.
- Include reasonable accommodation in the budget so that you can meet people's needs.
- Proactively invite people – contact different local Organisations of People with disability (OPDs) to widen your recruitment (including those for women or men, different impairment groups, older people, parents of disabled children).
- Provide disability awareness training and brief the whole team before you start.
- Check if people need braille or electronic documents in advance.

b. During the process – some impairment specific tips

- To make an environment physically accessible, it should be step free, easy to access (ramps, handles, handrails and lifts if necessary) and wheelchair accessible. Leave plenty of space. Make sure toilets are accessible, near your main meeting room, with wide doors, turning space, handrails and low basins.
- Provide orientation to the space for visually impaired people. Ask how they like to be guided as this varies. Tell them who is in the room. Don't all leave the room (for example for refreshments) without telling them where everyone is going! Remind everyone to verbally describe any visual images on slides or flipcharts. Provide large size font on signage and tactile signage if possible. If you have found out in the planning stages that people need braille or electronic documents, make sure they are available.
- When talking to a deaf person make sure you are facing them, talk normally, don't shout or slow down your speech, this doesn't help. Provide Sign Language Interpretation (check the interpreter uses the right sign language for the person) and visual information (for example, written and pictorial, including live transcription/subtitles). Provide a hearing aid loop system if possible.
- Use simple visual materials and clear spoken presentations so that people with cognitive impairments can follow the content. Allow for extra time for activities and repetition of information. Produce 'easyread' versions of key documents.
- Provide a calm quiet room nearby where people can take time out if the situation is too noisy and overwhelming.
- Allow flexible breaks and rests so that those with health conditions such as pain or who tire easily can rest and move about.

c. Following up

- When planning dissemination outputs, plan for easy-read written versions and in-person events in addition to long technical reports.
- Audio and video reports with transcription on the screen are useful.
- Ask people for their reflections using multimodal and visual methods such as emoticon rating scales and story methods.



Related resources

- Rohwerder B (2015) [Disability Inclusion: Topic Guide](#) Birmingham, UK: GSDRC, University of Birmingham
- CBM (2012) [Inclusion Made Easy: A quick program guide to disability in development](#) Bensheim, Germany: Christian Blind Mission
- Wickenden M and Lopez Franco E (2021) 'Chapter 24: Don't leave us out: Disability inclusive participatory research - why and how?' in Burns et al eds [The SAGE Handbook of Participatory Research and Inquiry](#) London: SAGE Reference
- WHO and World Bank (2011) [World Report on Disability](#) Geneva, Switzerland: World Health Organization and World Bank
- Shaw, J. and Wickenden, M. (2022) [Insights from Inclusive Participatory Fieldwork with Learners with Deafblindness and Other Marginalised Impairments](#), Brighton: Institute of Development Studies, DOI: 10.19088/IDS.2023.014
- Wickenden, M. and Thompson, S. (2023) [Insights from qualitative inclusive, participatory fieldwork with learners with deafblindness and women with disabilities in Bangladesh: Phase 2](#), Brighton: Institute of Development Studies. DOI: 10.19088/IDS.2023.032

Credits and other information:

This guide was authored by Mary Wickenden and peer reviewed by another disability researcher, Dr Mark Carew.

“Practical guides for participatory methods” is an introductory series, hoping to encourage practitioners and researchers to use participatory methods in their work. There are many other resources and training courses available for those who would like to specialise in participatory methods. This series is convened by the Participation, Inclusion and Social Change cluster at the Institute of Development Studies.

Please email participate@ids.ac.uk with any feedback you may have, including examples where you have used this method in practice. For more information on participatory methods, please visit participatorymethods.org where you can also find an electronic copy of this guide.

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