

Inclusion in research and evaluation: the missing 15%

by Philippa Smales

8 July 2020



Image: Twin-track representation. Two circular arrows pointing towards a person in a wheelchair. Text boxes outline strategies to include people with disabilities in mainstream and disability-specific development initiatives. (Image supplied by RDI Network 2020)

With the rapid world change we are seeing in regards to COVID-19, new ways of doing things are emerging quickly. NGOs and researchers are innovating, experimenting and ‘pivoting’; using their resources and connections, utilising old technologies such as mobile phone surveys, WhatsApp focus group discussions and of course video conferencing and remote collaborations. Although it is great to see the flexibility of response, there is a concern that a significant portion of the population is being forgotten, not on purpose, but they may be excluded nonetheless.

Globally, 15% of the world’s population are **estimated** to live with a disability, the majority in low- and middle-income countries. That means that in any research or evaluation carried out, we may be unintentionally excluding just over one out of every seven people in that community or sample group.

There has been some great work done in international development over the years in terms of research and evaluation targeting and including people with different disabilities. That work recognises that **knowledge and understanding** of the lived experiences of people with disabilities is essential for planning, implementing and evaluating the effectiveness of disability-inclusive development programming. However, there is still not enough awareness about how to ensure that people with disabilities have the same opportunity as people without disabilities to contribute to and benefit from mainstream development programming. This includes ensuring that people with disabilities have the same opportunity to influence and frame the research and development agenda.

To ensure research and evaluation is inclusive, RDI Network, CBM Australia, Nossal Institute for Global Health and the Pacific Disability Forum got together to produce *Research for All: Making Research Inclusive of People with Disabilities*. This blog provides a summary.

People with disabilities are often among the most marginalised, and may be subject to stigma or discrimination. Research or evaluation that excludes them can inadvertently reinforce this marginalisation. Of key importance to the conceptualisation of disability, as set out in the [United Nations Convention on the Rights of Persons with Disabilities](#) (CRPD), is the understanding that disability arises not only from impairment (a characteristic or condition in body functions or structures that affect difficulties in mobility, thinking, remembering, seeing and/or hearing), but also from the interaction between a person's impairment and the various barriers that they experience to full participation in areas of life.

Before embarking on any research project or evaluation process, it is essential to stop and consider whether the methods used will unintentionally exclude people with a disability – is there a barrier?

To effectively plan for meaningful inclusion, it is important to identify any locally developed solutions to the inclusion of people with disabilities throughout the research process. In order to ensure inclusivity, talk first to the local Disabled People's Organisation (DPO) – being mindful that they may be under-resourced and over-utilised, and that they may not represent all people with disabilities in the community such as people with psychosocial disabilities.

It may not always be possible for the research or evaluation to be inclusive of all people with disabilities; the cost, time factor and other considerations may render that impossible. However, reasonable accommodation should be considered. The term 'reasonable accommodation' or 'reasonable adjustment' refers to specific support or modifications, requested by a person with a disability, that are required to address a specific barrier to participation so that they are able to enjoy their rights on an equal basis with others.

Reasonable accommodation while doing research or surveying can be as simple as ensuring that surveys sent electronically are in an accessible format and easily readable by a screen reader. It could also include ensuring that important diagrams, pictures or photos that are part of the context are given a full description in the caption. When video conferencing, ensuring that there are no bright lights or background noise, that people speak one at a time, and that any important documents shared on screen are also downloadable or distributed in advance. If the research or evaluation utilises partners in country, discuss what methods may best promote inclusivity or will remove barriers to participation in that community.

Issues of consent are often raised when it comes to the inclusion of people with disabilities. People with disabilities and people with low literacy levels may be more comfortable with activity-based or verbal methods of information sharing, and may

provide consent by indicating verbally or with gestures or signs that they are willing to participate. The most important thing is if they can show understanding; that is, they can interpret and express back to the researcher, in their own words, their rights and the information shared with them about the research. If any concerns arise or it is decided to exclude them from the research, ensure the reasons are clearly explained.

Figure 1: The Consent Continuum

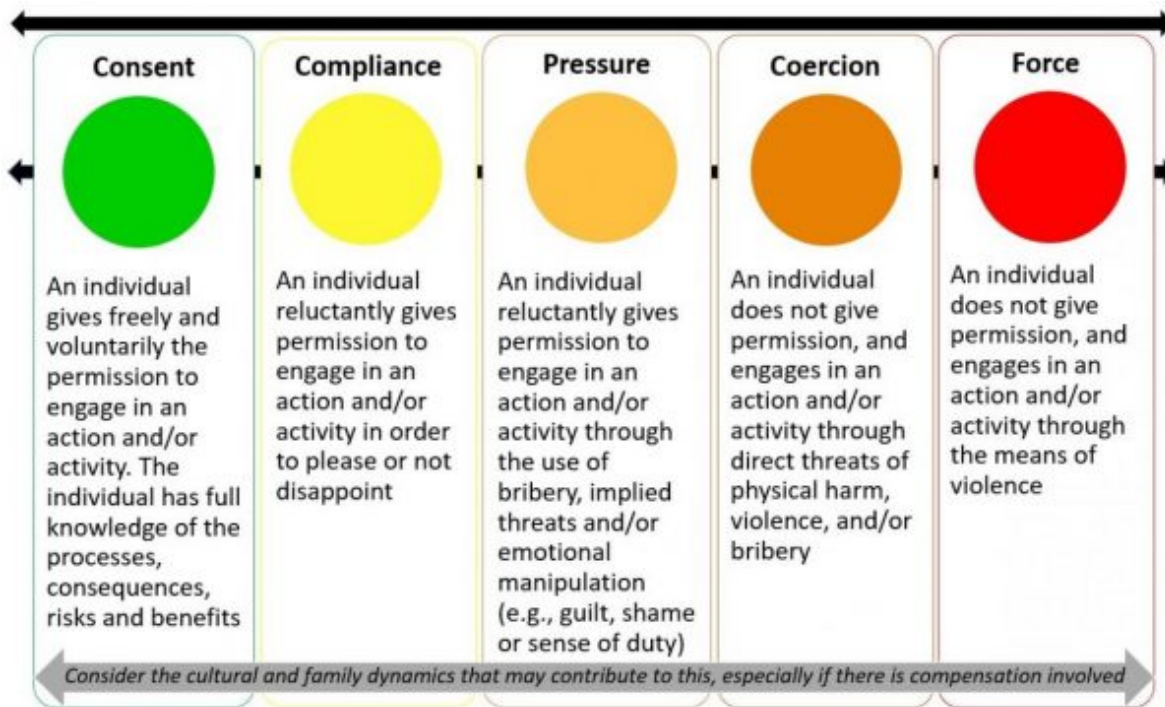


Figure 1: The Consent Continuum. An illustrated image with five circles (green, yellow, dark yellow, orange and red) laid out horizontally to indicate the spectrum of consent. The caption above each circle is Consent, Compliance, Pressure, Coercion and Force, respectively. There is text below each circle that gives a definition of each term. There are three double-sided arrows, one located above the image, one piercing the circles and one below the image to indicate that consent and non-consent flow backwards and forwards depending on context and situation. The final caption underneath notes 'Consider the cultural and family dynamics that may contribute to this, especially if there is compensation involved'. (Image supplied by RDI Network 2020)

Finally, if you have been inclusive in your research or evaluation information collection, you should also be inclusive in the dissemination and communication of that research. If the data is able to be disaggregated by disability without breaching confidentiality, that information may not only be useful for local DPOs but can provide people with disabilities information to be able to advocate on their own issues. The preparation of disability-inclusive research products should be based on the premise that all people like to use different ways to communicate and to receive information, and it is best to discuss with the community and local DPOs what

communication methods to use in that context.

Considering in advance and budgeting for the reasonable accommodation and inclusion of people with disabilities in research and evaluation will mean that more people in a community will be able to have a voice and shape development projects.

For more, see [Research for All: Making Research Inclusive of People with Disabilities](#), a report by RDI Network, CBM Australia, Nossal Institute for Global Health and the Pacific Disability Forum.

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Link: <https://devpolicy.org/inclusion-in-research-and-evaluation-the-missing-15-200708/>