

Good Examples

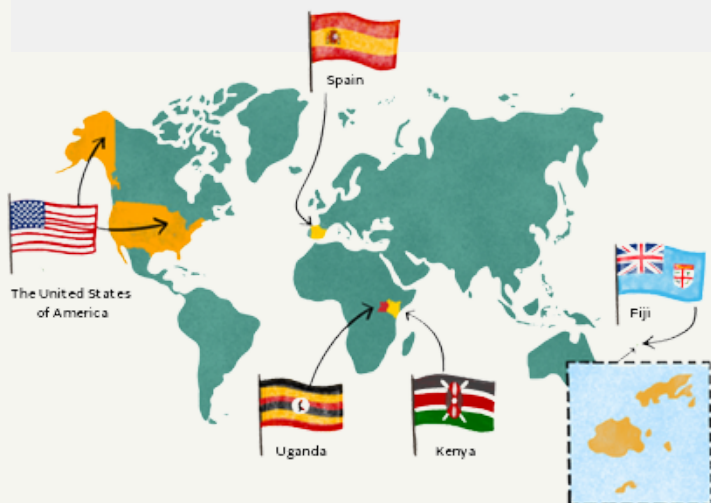
Inclusive focus groups for women with intellectual disabilities

About the Project

Inclusion International worked on a project with our partner, Women Enabled International, and members Liber in Spain, KAIH in Kenya, and SABE in the USA.

The project was about how women make choices about their sexual and reproductive health in different countries.

The project also included psychosocial disability organisations in Fiji and Uganda.



We wanted to find out if the right of women with intellectual disabilities to make decisions about their sexual and reproductive health is being respected in different countries.

To find this information out, we did research. We did this research through inclusive focus groups and interviews with women with intellectual disabilities.

The partner organisations used the Listen Include Respect guidelines to ensure this work was inclusive.



How we used Listen Include Respect

Listen Include Respect are international guidelines for organisations on how to include people with intellectual disabilities in different parts of their work.

The Convention on the Rights of Persons with Disabilities (CRPD) tells us that all people with disabilities have the right to “meaningful participation.” “Meaningful participation” is what happens when people with intellectual disabilities get everything they need to be fully included, participate equally, and feel valued.

The Listen Include Respect guidelines help organisations to make sure that this happens.

The guidelines include principles to follow and how-to checklists.

In this project, we used the guidelines in 4 main ways:

- Everyone followed the key principle of Believing In Inclusion
- We made sure there was self-advocate leadership
- We followed the guidelines to plan inclusive focus groups
- We created accessible information

I got to see the impact of these Guidelines myself. Using the Guidelines helped us to meaningfully include colleagues with intellectual disabilities in this project. Using these Guidelines has also made Women Enabled International a more inclusive organisation.

Elizabeth Schroeder, Women Enabled International



Believing in Inclusion

We made sure everyone working on the project understood what inclusion means for people with intellectual disabilities.

All project partners took part in briefing sessions on intellectual disability, inclusion, and Listen Include Respect. A self-advocate led these sessions.

Click here to see the:

- [Listen Include Respect briefing presentation](#)

There was a real commitment to collaboration. Different forms of knowledge were valued, including professional expertise, lived experience, and local context. I felt privileged to participate in those conversations. But the most important part was that the groups were led by self-advocates.

Nuria Gullio, Liber

Self-advocate leadership

Self-advocates were part of the project from the very start, including in planning.

In each Inclusion International member country, a self-advocate advisor was recruited. They co-led the work. Self-advocates were paid for their expertise and time.

The self-advocate advisors met together and supported one another throughout the project.

The self-advocate advisors were responsible for:

- Co-planning the research
- Planning how the focus groups will run in their countries
- Running the focus groups
- Supporting the focus group participants if they needed help
- Reviewing the findings
- Creating the final report
- Presenting the report at events



Inclusive focus groups

The Listen Include Respect focus group guidelines were followed in planning the meetings:

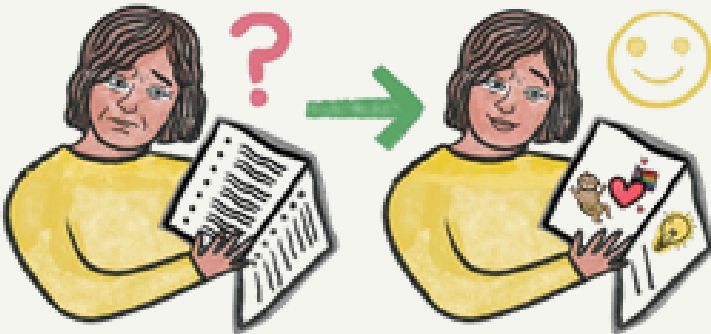
- The focus group facilitators were trained on how to run inclusive focus groups.
- A self-advocate led each focus group.
- Easy information about the focus group was shared in advance,
- The questions were easy to understand.
- There was plenty of time in the focus group agenda for discussions and breaks.
- The women who came to the focus groups were given an honorarium to cover their time.

Some of the questions that were asked in the focus group may have been upsetting. The self-advocate advisors offered support to the women taking part, and the group received information about local support services they could access afterwards if needed.

The focus groups were not inclusive of all women with intellectual disabilities. For some women with complex disabilities and high support needs, we conducted 1-1 interviews. We created additional resources for supporters of women with high support needs to help them prepare and understand what was happening.

Click here to see the:

- [Training on inclusive focus groups](#)
- [Information about the focus group](#)
- [Information for supporters of women with high support needs.](#)



Accessible Communication

All project meetings followed the Listen Include Respect Meeting Guidelines. This meant meetings were planned so that everyone could take part and share their ideas.

Every document was written in plain language, had an easy-to-understand version, and was checked by self-advocates. For example:

- The self-advocate advisor job description
- The focus group agenda
- Consent forms
- The final report

The self-advocate project advisors worked together to become a reference group to review the final report.

Over several meetings, the group:

- Reviewed the findings of the research
- Gave feedback on the conclusions and recommendations
- Decided how the final report should look and be organised
- Wrote the easy-to-understand version of the report
- Designed and gave feedback on the formal illustrations used in the easy-to-understand version

Click here to see the:

- [Self-advocate advisor job description](#)
- [Easy-to-understand final report](#)

Easy-to-understand information is important so that everyone is able to understand what is being talked about and be able to give their opinion and work as an equal partner.

Tia Nelis, Inclusion International

Challenges

We faced challenges with using the guidelines during our project:

Amount of information to cover in the focus groups and report.

It was a challenge to make sure the report was detailed without being too long.

Language and interpretation.

Working across different countries and languages was difficult. Our colleagues at Liber in Spain did excellent work reviewing the Spanish version of the report to make sure it was accurate and accessible.

Inclusion of harder-to-reach people.

Reaching all women with intellectual disabilities, including those with higher support needs, needed extra planning. With more time and budget, we could have reached more women.

Working remotely

Some parts of the project happened online. Some self-advocate advisors needed extra support to take part in virtual meetings. This meant additional planning, time, and budget were needed to make sure everyone could participate fully.

Sharing results with groups and next steps for work

After we made the report, we needed to think more about how to share the findings back with the women who took part, and support them in thinking about how to use the research and what comes next.



I believe that including advocates to lead is very important. Advocates also bring what they have learned and their own lived experience when presenting and leading to others.

Diana Mairose, SABE



Key Recommendations

If you are planning similar work, these are our recommendations:

Work with local organisations of people with disabilities. Ask them to help plan and lead the work. They know their communities best.

Include self-advocate leaders in all parts of your project. Self-advocates should be involved from the very beginning — not just during activities. Their ideas and experiences strengthen the project. Make sure they are paid for their expertise and time.

Make sure everyone understands inclusion and accessibility. Do not assume people already know how to work inclusively. Build in time for training at the start.

Plan with plenty of time and budget.

Inclusive projects take longer to plan and cost more. Budget for accessible materials, honorariums, support persons, accessible venues, and extra preparation time. Do not treat inclusion as an add-on.

Be creative when designing focus group activities. Use stories, illustrations, role-plays, and other accessible activities. These work much better than asking lots of questions in a formal meeting.

Value the process as much as the outcome. Working inclusively with self-advocates builds knowledge, trust, and relationships that go far beyond any single project. These connections are valuable in themselves.



More information

For more information on this project, you can:

- [Read the “technical” report here](#)



The Listen Include Respect Guidelines were essential to make the Legal Capacity Project more inclusive. Thank you, Inclusion International and Down Syndrome International, for creating such an important document to guide our work towards inclusion.

Alana Carvalho, Women Enabled International



For more information on Listen Include Respect and how you can also run inclusive projects visit: listenincluderespect.com/projects