

A Learning Report:

Including Adolescent Girls with Intellectual Disabilities in Humanitarian Action

December 2024



Thank you!

A partnership between the International Rescue Committee (IRC) and Inclusion International made this work possible. This shows why it is important for big humanitarian organizations like IRC to work with organizations of people with disabilities like Inclusion International.

We were able to find adolescent girls with intellectual disabilities to take part because we worked with Inclusion International's member organizations in Ethiopia and Burkina Faso.

This is a good example of how future partnerships should work.

We want to say a big thank you to everyone who helped with this work:

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French Translator and Interpreter: Mariana Virginia Arias Llano

Illustrator: Natalie Hughes

Cover photo: This is a focus group with adolescent girls with intellectual disabilities in Ethiopia.

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This Learning Report is for:

- People who work for humanitarian organizations in global and country offices.
- People who work for community and representative organizations in global and country offices.



About this document

The International Rescue Committee (IRC) and Inclusion International are working together on a project.

The project is about understanding how organisations like IRC can better include adolescent girls with intellectual disabilities who had to leave their homes because of emergencies.

“Adolescent girls” means girls who are ages 10-19.

The project is happening in Ethiopia and Burkina Faso. The work started in 2023 and will continue until 2025.

This report is about what we learned in the first year. In this report, we will share:

- How we worked on the project
- What we heard from focus groups of adolescent girls with intellectual disabilities and their caregivers
- What we learned doing this work
- Tips that you can use in your work



How we worked on this project

Why did we do this work?

We did this work to help humanitarian organisations include people better. Humanitarian organisations are groups of people who go to places where people are living through emergencies like wars or disasters, and they help the people there.

Humanitarian organisations often do not know how to include people with intellectual disabilities in their work. This is a problem because:

- Girls and women with disabilities are 2 to 3 times more likely to experience violence than those without disabilities
- Girls with disabilities are less likely to go to school than other girls
- Girls and women with disabilities often can't get the healthcare they need
- People with intellectual disabilities are often left out of humanitarian aid



Who worked on this project?

The International Rescue Committee (IRC) and Inclusion International worked together on this project.

- The IRC helps people who are going through emergencies
- Inclusion International is a network of organisations that work on the rights of people with intellectual disabilities

IRC and Inclusion International worked with our local partners on this project:

- In Ethiopia: [Fikir - Ethiopia National Association on Intellectual Disability \(FENAID\)](#)
- In Burkina Faso: [Association des Parents et Amis d'Enfants Encéphalopathes \(APEE\)](#)
- IRC local teams in Ethiopia and Burkina Faso

This project was possible and successful because of a strong partnership.



This photo shows the FENAID and IRC team in Ethiopia. This was after FENAID trained IRC.

We also created a group of advisors. Their role was to give us advice and feedback as we were working. This group included:

- People with intellectual disabilities
- Organisations led by women
- Humanitarian organisations
- Experts from different countries

To make sure the work we did was inclusive, self-advocates were part of all the work. Self-advocates are people with intellectual disabilities who know about human rights and who advocate about rights on behalf of themselves and others.

Self-advocates were part of the project teams that ran the focus groups, and the advisory group.

We followed [Listen Include Respect](#) guidance to help make sure our work was accessible and inclusive. [You can read much more about this in our good example here.](#)



[Click here to learn more about using Listen Include Respect](#)

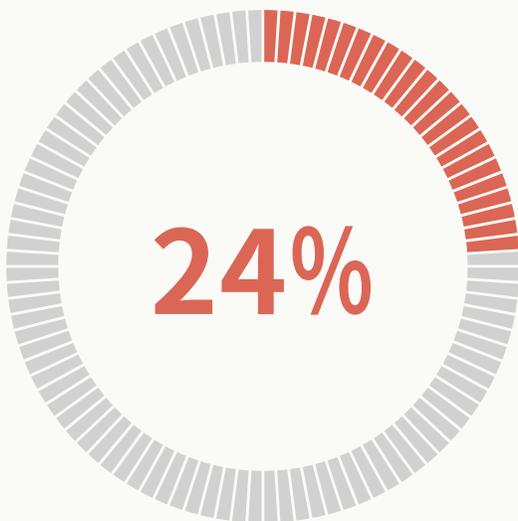
What we did

What did we do?

At the start of the project, we did some research:

- We looked into what similar work has happened before
- We asked humanitarian organisations about how they include girls with intellectual disabilities
- We asked Inclusion International members about how they worked with humanitarian organisations

From our research, we found out that most humanitarian organisations didn't know how to include girls with intellectual disabilities in their work well. Humanitarian organisations wanted tools and training to help them do this work better.



of people said their programs had successfully included adolescent girls with intellectual disabilities

Next, to understand **how** humanitarian organisations could do better, we planned focus groups. Focus groups are meetings where people can share their ideas and give feedback about a topic.

We wanted to hear from girls with intellectual disabilities about their experiences. We wanted to know what they thought could be improved.

To plan the focus groups we worked with APEE and FENAID, local organisations of people with disabilities in Ethiopia and Burkina Faso.

APEE and FENAID helped to find and invite girls with intellectual disabilities and their caregivers to the focus groups. APEE and FENAID advised about the situations of people with intellectual disabilities in Ethiopia and Burkina Faso so that the focus groups worked well for the girls and their caregivers.

FENAID and APEE helped IRC find and invite girls, and their caregivers to take part in the focus groups.



This photo shows the APEE and IRC team in Burkina Faso. This was after they worked together to lead the focus groups.

The project team worked hard to make sure the focus groups were easy and inclusive:

- We talked to 24 adolescent girls with intellectual disabilities
- We also spoke to their caregivers
- We asked the girls and their caregivers questions about getting help from humanitarian organisations
- We created stories with pictures to help the girls understand the questions we were asking them
- Self-advocate women from APEE and FENAID co-led the sessions
- The girls brought someone they trusted to be with them
- We took breaks when the girls needed them
- We used activities like games, dancing, and role plays to make it more interesting



The focus groups happened in both countries in July 2024.



Selam Asgedom Berhe is a self-advocate who lives in Ethiopia. She co-led the focus groups with girls. Here she is practicing with IRC and FENAID staff before the focus groups.



Pélagie Yameogo is a self-advocate who lives in Burkina Faso. Here she is co-leading a focus group with girls. She is telling them the story about a girl who had to leave her home because of a war.

What we heard from the focus groups

Challenges the girls and their caregivers face

Through the focus groups, we found out that adolescent girls with intellectual disabilities and their caregivers faced many challenges.

Many girls were afraid to leave their homes. Some girls faced bullying at school.



“ Being with new people makes me feel afraid. And I didn't know the place, so that's why it makes me afraid.

Adolescent Girl, Ethiopia

I am not comfortable going to school. Because my classmates beat me, and they asked me to give them the biscuits that I have received in school.

Adolescent Girl, Ethiopia”

Caregivers said they felt excluded:

- Many caregivers are taking care of their daughters alone
- Some girls need a lot of support and caregivers find it hard to work when they need to be with their daughters all the time
- Many caregivers feel alone with their problems

When you're the parent of a child with disabilities, you're no longer free to move around, and financially all expenses are directed towards [my daughter]. I no longer have any freedom.

Caregiver, Burkina Faso



Girls and caregivers said they faced challenges getting help from humanitarian workers:

- Aid workers often didn't understand about intellectual disabilities
- Girls and their families didn't get information about help that was available
- Sometimes, they were promised help but didn't receive it
- The places where aid was given out were often too crowded



No one has ever come to tell us about aid distributions. It's through other people that we learn about them.

Caregiver, Burkina Faso

I can't go there, it's because of the people. People run to get there and when I want to go, they stop me.

Adolescent Girl, Burkina Faso

The girls with intellectual disabilities felt left out:

- Many girls said they didn't have friends
- People in the community often treated them badly
- No one asked the girls what help they needed
- Some programs wouldn't let them join



No, I don't have any friends. I walk alone.

Adolescent Girl, Burkina Faso

At home, [my daughter] isn't bothered, but outside the house, people don't like her. When she drinks from a cup, no one else wants to use the same cup, not even her own brothers.

Caregiver, Burkina Faso

This is my first experience of having my opinions about my child taken into account.

Caregiver, Ethiopia

Recommendations for humanitarian organisations

Through the focus groups, the girls and their caregivers told us what humanitarian organisations need to do better:

Talk directly to girls with intellectual disabilities and their families. Ask them what they need. Tell them about available help.

“ If there's aid for us, we can be called by telephone to let us know, as was the case for these consultations.

Caregiver, Burkina Faso

It's the way you went about including us in the consultation that you should do to include us in future projects. You have to come to us to include us since we have disabilities.

Adolescent Girl, Burkina Faso”

Make it easier and safer for girls and their families to get help. This might include helping them get to the places where aid is being provided or having separate times to give out aid to people with disabilities.

“

They should be registered by category, those with disabilities on one side and those without disabilities on the other, to enable them to benefit separately.

Caregiver, Burkina Faso

”

This is an IRC Women and Girls Wellness Center in Ethiopia where we did focus groups. We worked hard to make it easy and safe for girls to take part.



Invite and include girls in all activities, make activities fun and welcoming, and help girls make friends. Staff should get to know the girls.



Coming and participating in the safe space refreshed me, having your friends and playing here makes me refreshed.

Adolescent Girl, Ethiopia

If they can participate in the Women and Girls Safe Space activities or any other services, they can manage their stress and I believe it is refreshing, so it would be a way to manage their stresses.

Caregiver, Ethiopia



The team led fun activities during the focus groups. This is in Burkina Faso.



Understand how the girls would like to be treated by asking them directly!



Girls in Ethiopia listening to stories about a girl named Mara. This helped them talk about their own experiences. They told us about what they need, and how they want aid workers to treat them.

Girls in Ethiopia doing role plays to show us how they want to be treated. They showed us how they want aid workers to talk to them clearly and with respect.



Help the girls and caregivers understand their right to be included and make sure staff, services, and activities are inclusive!



IRC staff leading a fun activity to welcome and include girls in Burkina Faso.

Make sure the girls are supported with their menstrual hygiene, health, and other basic needs. Help caregivers to support their children during adolescence with information and resources.



I want to tell the organisation to support us, to provide us sanitary pads, underwear, and other materials for hygiene.

Adolescent Girl, Ethiopia

Let someone come and give my child advice.

Caregiver, Burkina Faso

I don't even know how to tell her things. I don't even know how to inform her about things. I want the organisations to help me. I want the organisations to know that I am stressed. And I want the humanitarian aid workers to understand me.

Caregiver, Ethiopia



Help girls learn skills so that they can earn money and support themselves.



I want to tell the organisations to teach us skill building, so I want to engage in skill building.

Adolescent Girl, Ethiopia

Help for my daughter must be continuous and not one-off. Help that isn't money but an activity that can generate money.

Caregiver, Burkina Faso



Note: Many national organisations that represent people with intellectual disabilities and their families have programs that support skills building or income generation. Humanitarian organisations should find out if OPDs in the area have programs like these, and how adolescent girls with intellectual disabilities can be included.

Listen to what skills the girls already have and help them build on them, helping them feel confident and useful.

“

I am good at drawing. So I can draw a picture in the Women and Girls Safe Space.

Adolescent Girl, Ethiopia

I want the organisations to provide embroidery thread and embroidery needles so that I can work on that because I have the skills.

Adolescent Girl, Ethiopia

I can help them to provide the service wholeheartedly. So, we can [help] by participating in different activities by coming and taking part in the activities such as embroidery.

Adolescent Girl, Ethiopia

”



Support caregivers by creating spaces for mothers to come together and share experiences. These meetings should be led by peers. Representative OPDs can help organize them.

“

I have no one to turn to, to share my problems.

Caregiver, Ethiopia

I think we need to set up an association for people with disabilities so that if there's information, we can give it to the relevant people. [...] When they want to give us support, we are told to come to them but it's difficult for me to come with my daughter.

Caregiver, Burkina Faso

”

Caregivers talking about their experiences during a focus group in Ethiopia.



Support caregivers to build skills and provide for their families, including giving money to start small businesses. Caregivers say this would help their families with stress.

I want the organisations to understand that she has special needs. I want the organisations to understand that my daughter has a disability. I want the organisations to support me.

Caregiver, Ethiopia

I would be happy if you could provide us a start-up capital. So if you can give us a start-up capital, I can have a store. And I can open a restaurant so I can provide food for people. I can sell food. So I would be happy if you could provide me a start-up capital.

Caregiver, Ethiopia

I would like to be supported in breeding and agriculture. I would like to do small trade.

Caregiver, Burkina Faso



What we learned from doing this work

This work taught us that including girls with intellectual disabilities in humanitarian work is very important. Girls and their caregivers have the right to take part in humanitarian services and programs, feel safe and respected and have their voices heard.

From our work, we learned that humanitarian organisations need to change how they work to make sure girls with intellectual disabilities are better included.

Girls taking part during a focus group in Ethiopia. The aid workers showed the girls respect and listened closely to what they said.



What humanitarian organisations need to do:



- ◆ Make sure staff understand intellectual disabilities better. Staff need training to understand intellectual disabilities. This will help them provide better support and not forget about people with intellectual disabilities.
- ◆ Talk to girls and their families. It's important to ask girls and their caregivers what they need. Keep girls and caregivers informed about what help is available and how they can get it.
- ◆ Make it easier to get help. Organisations should plan ways for girls with intellectual disabilities and their families to get help safely. All activities and spaces should be designed to be accessible and include everyone.

- ◆ Support basic needs and skills. Girls need help with things like menstrual health. They also need to learn skills that can help them earn money. Caregivers need support, too - they should get help learning how to support their girls during adolescence and find ways to earn money for their families.
- ◆ Help stop bad treatment. Create friendly spaces where girls can make friends and feel welcome. Work with the community to help them understand and support girls with intellectual disabilities.
- ◆ Think about the barriers that we create. There are a lot of barriers that we need to be aware of that stop girls and their caregivers from being included. These might be how we communicate and how we run activities. Once we understand how we are creating barriers we can work to change things.

Why humanitarian organisations and organisations of people with disabilities working together is important:



Working together with organisations of people with disabilities helped make our project better.

Here is what we learned:

- ◆ Work with organisations that represent and understand intellectual disabilities. We learned it's good to work with both international and local organisations. Partners should make decisions together. Everything should be planned together from the very start.



Getting advice from others made our work stronger. We got advice from different experts. We made sure to include self-advocates who are experts with lived experience from the start and throughout the project.



Keeping girls at the centre of everything we did. We always thought about what would be best for girls with intellectual disabilities as we were planning and doing our work. We listened carefully to what the girls said they needed.

What happens next?

The IRC and Inclusion International will work together to create training materials for humanitarian organisations. This will help humanitarian organisations include girls with intellectual disabilities better. We will also help organisations of people with disabilities work better with humanitarian organisations.

Sharing our tips

Here, we have collected some Tip Sheets. These are the top things we learned from doing the project together that might help you to do similar work.

The Tip Sheets are:

1. Humanitarian Organisations and Organisations of People with Disabilities Working Together as Project Partners
2. Running an Inclusive Advisory Group for People with Intellectual Disabilities
3. Running Inclusive Consultations or Focus Groups



Tip Sheet 1: Humanitarian Organisations and Organisations of People with Disabilities Working Together as Project Partners

Here are some tips for working together on a project.

Good ways to work together:

- Share power
- Make decisions together
- Respect one another's knowledge
- Talk about what you want to do at the start
- Make sure everyone knows their role
- Have project team meetings regularly, we met every two weeks
- Make project plans everyone can understand
- Take time to build relationships

Include people with intellectual disabilities:

- Include self-advocates in planning from the very start
- Value their advice
- Make everything as accessible as possible, and follow guidelines like [Listen Include Respect](#)
- Use simple language
- Make documents easy to understand
- Give people time to share their ideas

Remember:

- Small organisations might have fewer staff and less time and resources
- Local organisations know their community best
- Try to be flexible with plans as much as possible. Changes to your project plan may need to happen quickly



Tip Sheet 2: Running an Advisory Group that includes People with Intellectual Disabilities

Advisory groups can help your project be better and more inclusive. They can give you feedback and advice when you need it.

You can use the [Listen Include Respect guidelines](#) to plan Inclusive Meetings. This Tip Sheet also collects what we found.

Setting up the group:

- Include people with different experiences. For example, in our group, we had experts from women's rights organisations, organisations of people with disabilities, humanitarian organisations and universities
- Make sure everyone understands the work
- Include self-advocates with experience

Making meetings work well:

- Use simple language
- Send information early so people can prepare - two weeks in advance is best
- Make sure everyone can share ideas
- Use activities that everyone can join in
- Make sure everyone feels included
- Value all ideas



The friendly and safe atmosphere during the meetings was truly remarkable. Everyone's opinion was valued.

Inclusion Advisory Group Member





Tip Sheet 3: Running Inclusive Consultations or Focus Groups

Consultations or Focus Groups are often more accessible and inclusive than surveys for gathering information from people with intellectual disabilities. The results you get are often more useful.

You can use the [Listen Include Respect guidelines](#) to plan an Inclusive Focus group. This Tip Sheet also collects what we found.

Before the consultation:

- Choose a self-advocate to be part of the facilitation team
- Choose a quiet, private place
- Make sure everyone can get in and move around easily
- Plan for meetings to be 2½ hours or less

- Split longer meetings over two days
- Have support ready if people need it or get upset
- Make sure facilitators practice together and that everyone knows their roles
- Have notetakers
- Do not have observers or many extra people who do not need to be there.

Setting up the room:

- Make a small circle so everyone can see each other
- Use mats or cushions to make it informal
- Only have women in the room
- Have comfortable seating
- Make sure there's good air and light



When we made the circle smaller and moved closer together, the girls began to smile and talk more.

Focus Group Facilitator



Making everyone feel welcome:

- Keep the group small
- Smile and make eye contact
- Learn and use everyone's names
- Let people sit in a way comfortable to them, for example, close together or on the floor
- Start with fun activities like icebreakers
- Use local music and dancing
- If people need support let them bring someone they trust
- Give lots of praise

During the consultation:

- Have breaks and snacks
- Let people take rests when they need to
- Be patient when waiting for answers
- Change activities if people seem tired
- Keep checking if everyone understands
- Make sure no one is left out

Asking questions:

- Using pictures, stories, and role-plays helps people with intellectual disabilities understand the topic easily
- Make sure the pictures and stories are about local people and places
- Keep questions short and open and easy to understand
- Do not ask more than one question at a time
- Give plenty of time for answers

Good ways to encourage people to take part:

- Clap for everyone's ideas
- Thank everyone for sharing, celebrate all types of participation
- Let people encourage each other
- If you are working with women or girls, have female facilitators



One girl gave another girl a fist-bump after she answered. Then everyone started clapping!

Consultation Team Member



Remember:

- Be flexible and ready to change plans
- Watch how everyone is feeling
- Keep everything fun and friendly
- Let people answer in their own way
- Be patient and kind



Engaging girls in a focus group in Burkina Faso.

For more information, please contact:

International Rescue Committee
vprumailbox@rescue.org;
children@rescue.org

The International Rescue Committee (IRC) helps people affected by humanitarian crises to survive, recover, and rebuild their lives.

Inclusion International
info@inclusion-international.org

Inclusion International is the global OPD network representing people with intellectual disabilities and their families.

