

Reflections on a Rights-Based GBV Response from Self-Advocates with Intellectual Disabilities in Lebanon and Kenya

A Learning Brief from the Early Marriage in Crisis Project

February 2024
IRC's Violence Prevention and Response Unit
For Internal and External Use

INTRODUCTION



Within the humanitarian sector, there is a significant gap in how to engage appropriately and effectively with persons with intellectual disabilities,¹ let alone how to identify and respond to their needs. This is especially the case with sensitive issues, such as gender-based violence (GBV). Women and adolescent girls with intellectual disabilities are two of the most likely groups to be targeted for abuse by perpetrators. Over the course of the International Rescue Committee's (IRC) Early Marriage in Crisis project funded by the U.S. Bureau of Population, Refugees, and Migration, IRC teams came to recognize a particular lack of understanding amongst the project team and humanitarian actors in general, around (1) how women and adolescent girls with intellectual disabilities understand GBV, and (2) their preferred ways of communicating and receiving information about GBV.

To gain insights into these critical areas, IRC partnered with Inclusion International and two national organizations representing people with intellectual disabilities and their families in Lebanon and Kenya: the Lebanese Association for Self-Advocacy, and the Kenya Association of the Intellectually Handicapped, respectively. The intention was to begin answering these questions directly from the perspectives and lived experiences of women and adolescent girls with intellectual disabilities who are self-advocates.²

This learning brief discusses the findings of the two consultations and areas that may merit further exploration. The brief also includes overall lessons from the IRC Lebanon country program team and Inclusion International, both of which have worked extensively with organizations of persons with disabilities (OPDs), on how international NGOs like the IRC can effectively and appropriately partner with OPDs in the future.

¹ People with intellectual disabilities are individuals who experience barriers to inclusion based on actual or perceived cognitive functioning and skills. People with intellectual disabilities face barriers that make it more difficult for them to take part equally in their communities, but with support and through more accessible systems they can be fully included in all parts of their lives. Some examples of areas where people with intellectual disabilities might need support in their lives includes communications, understanding, problem solving, and self-care.

² Self-advocates are people with intellectual disabilities who speak up for themselves about the things that are important to them. The self-advocates in Inclusion International's network do 3 important things: understand their rights, work as a team to support and learn from each other, and speak up about what would make life better for them and other people with intellectual disabilities.

SUMMARY OF KEY FINDINGS

1. While all self-advocates were able to identify violence (in particular GBV), they emphasized that this might not be the case for all adolescent girls with intellectual disabilities, due to barriers they may face in accessing information about GBV and reporting mechanisms, and high levels of community stigma.
2. Community stigma, perpetrator profiles, and a lack of access to information and reporting mechanisms represent the main barriers to identifying and reporting GBV faced by adolescent girls with intellectual disabilities.
3. A supportive environment is one of the keys enabling factors for adolescent girls with intellectual disabilities to report GBV.
4. Adolescent girls with intellectual disabilities who have experienced GBV prioritize reaching out to local community-based organizations who can support them with their immediate needs as well as play a key role in empowering them to claim their rights.

METHODOLOGY

This learning brief integrates data from two focus group discussions (FGDs) with 11 self-advocates with intellectual disabilities (10 female, 1 male). In Lebanon, all participants were female and in Kenya, five females and one male participated in the consultation. The data collection approaches (including selected countries and organizations, sample, tools, and approach) were identified through thorough consultations with Inclusion International and national partners (the Lebanese Association for Self-Advocacy [LASA] and the Kenya Association of the Intellectually Handicapped [KAIH]). To gauge understanding of GBV as a concept, the FGDs featured short stories (see Annex 2 for the stories used in the FGDs), followed by questions to further open the conversation. The FGDs were facilitated by IRC country program staff in March 2022. They were conducted via Zoom in Lebanon, and in-person in Kenya.

Focus Group Discussions with Self-Advocates



N = 5 in Lebanon



N = 6 in Kenya

LIMITATIONS

The findings of this learning brief are sourced from two consultations (one per country) with self-advocates, and therefore are not fully representative of the diverse experiences of adolescent girls with intellectual disabilities. The experiences of adolescent girls with intellectual disabilities will also vary based on the type and severity of their impairment and the local context. The consultations were initially designed to uncover some data around GBV and early marriage amongst adolescent girls with intellectual disabilities. However, most self-advocates had not heard of early marriages taking place amongst adolescent girls with intellectual disabilities. Therefore, the consultations focused mainly on GBV, including their reflections on adolescent girls' experiences of GBV, barriers to accessing response services, and their recommendations to address these barriers.

KEY FINDINGS

1. EXPERIENCES AND UNDERSTANDING OF VIOLENCE

All five self-advocates in Lebanon reported that adolescent girls with intellectual disabilities face violence or harm in their communities. Most self-advocates described some form of physical abuse (using words such as "beating," "battering") and verbal abuse ("unpleasant words," "yell").

When presented with a short story about an adolescent girl with an intellectual disability named Samia who experienced an abusive early marriage, all five self-advocates in Lebanon described the scenario as "violence." Other adjectives used to describe what happened included "evil" and "cruel." In Kenya, one self-advocate used the word "suffering" to describe Samia's situation.

100% of Lebanese self-advocates (5 of 5) included "violence" or "violent" in their description of what happened in the story about Samia

All self-advocates participating in the consultations identified the situation in the story as violence (GBV), while emphasizing that they did not personally experience this type of violence or abuse themselves. However, they emphasized that adolescent girls with intellectual disabilities may not recognize this as violence due to the barriers they face in accessing information about GBV and reporting mechanisms along with high levels of community stigma.

"[A] girl with intellectual disabilities does not differ between right and wrong. Sometimes she might think that something is not wrong. She is not able to identify violence, she does not know how to talk about it."

- Lebanese self-advocate

100% of Lebanese self-advocates (5 of 5) reported that adolescent girls with intellectual disabilities face violence or harm in their communities

2. BARRIERS TO IDENTIFYING AND REPORTING GBV

PERPETRATOR PROFILES

Perpetrators of violence and abuse are often 'trusted' individuals, which can make it more difficult for adolescent girls with intellectual disabilities to identify GBV and report it. However, during these consultations, many of the self-advocates clearly identified the perpetrators in the stories. As noted above, this may be because they have had greater access to information about GBV – perhaps through participation in their respective groups.

When reflecting on Samia's story, three participants in Lebanon pointed out the father's role in the early marriage. They highlighted that the adolescent girl was not equipped for motherhood, and pointed out the father's verbal abuse ("yelled at" and "insulted") and his role as a "perpetrator" for separating the mother and child.

In Kenya, one self-advocate explained how she avoids "familiarities" with boys from her community to protect herself from GBV and recommended that all girls with disabilities do the same. Another reported that adolescent girls with intellectual disabilities experience violence from individuals trusted by the community such as pastors, doctors, and parents.

"Her father was very cruel with her, he didn't let her express what she wants, and then her husband was very violent with her. When she returned to her parents' house, it was a cry for help, this is torture."

- Lebanese self-advocate

“They [family] lock them inside the house, they don’t let them go out unless they are getting married. They beat them in the house and treat them in a bad way like a maid.” - Lebanese self-advocate

COMMUNITY STIGMA

Both Kenyan and Lebanese self-advocates also described community stigma and discrimination against adolescent girls with intellectual disabilities. For instance, they highlighted social isolation due to the family being ashamed or caregivers restricting the girls’ movement. One Lebanese self-advocate described how these girls (and their experiences of abuse) may be “hidden” away from most of society in homes or institutions. In Kenya, the self-advocates reported that the families of adolescent girls with intellectual disabilities will not support their decision to leave an early marriage due to “shame.”

If the family is the source of violence, three Lebanese self-advocates said that Samia would “need to go to the police” for support.

In contrast, in Kenya, one self-advocate reported that the police tend not to believe adolescent girls with intellectual disabilities and that some officers may be perpetrators of violence themselves. It was noted that adolescent girls with intellectual disabilities from a refugee background will also be very unlikely to go to the police.

“They are hidden at home or in an institution. If they run away, lacking proper information, they can be hurt. More for the girls with intellectual disability, for sure they can get hurt a lot when being told that their place is not in this world.” - Lebanese self-advocate

“It is very difficult for someone living with a mental disability to go to the police...because they cannot believe you when you are accusing someone of violence.” - Kenyan self-advocate

LACK OF ACCESS TO INFORMATION AND REPORTING MECHANISMS

High levels of stigma and isolation often result in adolescent girls with intellectual disabilities having no access to information about what violence is and how to report it. All Lebanese and Kenyan self-advocates pointed out that, from their perspective, most adolescents with intellectual disabilities would not be able to identify and report violence. The participants agreed that all adolescent girls experience some level of violence. They pointed out the unique barriers that are faced by adolescent girls with intellectual disabilities when it comes to identifying and reporting GBV, and the lack of external support.

In Lebanon, two self-advocates also talked about how adolescent girls with intellectual disabilities may not be able to defend themselves or be able to identify and talk about violence. They further described the barriers faced by Samia when it comes to reporting, pointing out that she did not have the "right to speak" in her society, that her father was unwilling to consider and respect her opinion, and that she was afraid of her husband.

"Girls with intellectual disabilities are the most exposed to violence because people think that they lack information [and] knowledge. [The girls] know everything, but it's the people who don't know."
- Lebanese self-advocate

As highlighted in this section, community stigma, the profile of perpetrators, and a lack of access to information and reporting mechanisms are the main barriers faced by adolescent girls with intellectual disabilities when it comes to identifying and reporting GBV.

3. STRENGTHENING COMMUNITY-BASED GBV RESPONSE

SUPPORTIVE FAMILIES AND COMMUNITIES ARE KEY ENABLERS FOR ADOLESCENT GIRLS WITH INTELLECTUAL DISABILITIES TO REPORT GBV

When considering what might happen if Samia reported her experience, the Lebanese self-advocates felt people might respond in either positive or negative ways (often depending on whether they are "good people" or "bad people"). Two Lebanese self-advocates described how someone might be "shocked at first" or "not believe [Samia]." However, the self-advocates generally seemed to encourage Samia to seek out a "good person," especially someone she knows, trusts, and who "treats girls right."

Three participants suggested that someone from her family (particularly her mother or from her mother's side), might be better able to support her than someone external, though one self-advocate felt the response was not dependent on whether the person knew Samia. One self-advocate also noted that if the family was the source of violence, it would be difficult to seek help.

A supportive environment is one of the keys enabling factors for adolescent girls with intellectual disabilities to report GBV. This needs to be present at the family level but also in the wider community. Self-advocates emphasized the need for awareness-raising activities for families and the wider community to end the stigma around disability and GBV and support the adolescent girls with reporting GBV.

ADOLESCENT GIRLS WITH INTELLECTUAL DISABILITIES ARE MOST LIKELY TO SEEK OUT SUPPORT FROM COMMUNITY-BASED ORGANIZATIONS

None of the respondents in the FGD identified UN agencies or INGOs as potential avenues for Samia to report her experience. When asked where adolescent girls and women like Samia could seek help for similar situations in their community (in general), 4 of the 5 Lebanese self-advocates recommended that Samia seek help at women's rights organizations or organizations "who help battered women," while two self-advocates named a specific local organization.

"There are organizations who know women's rights so she can talk about herself. If she goes to someone else, they might beat her."
- Lebanese self-advocate

Lebanese self-advocates felt that these organizations could provide "moral help" and support, including empowering the girls to defend themselves. They could also strengthen the understanding of the adolescent girls by explaining the different types of violence, and provide financial help. In addition, the police could "punish the bad person." In Kenya, participants highlighted the girls' needs with intellectual disabilities to "get the strength to be with other people" and for organizations to "empower them by identifying their capacities and strengthening them."

"It is all about detecting their strengths." - Kenyan self-advocate

According to the self-advocates, adolescent girls with intellectual disabilities who have experienced GBV are most likely to first seek support from local community-based organizations. They highlighted that in addition to providing support, these organizations also play a key role in empowering adolescent girls with intellectual disabilities to claim their rights. Humanitarian actors should therefore find ways to partner with and support these community-based organizations to provide quality response services as part of the GBV referral pathways. It is recommended that partnerships between INGOs and local community-based organizations not be limited to funding support only, but also extend to capacity-sharing such as: visibility support within the community, co-creation of community awareness-raising messages, and tailored capacity-building plans.

RECOMMENDATIONS

RECOMMENDATIONS FOR INCLUSIVE COMMUNICATIONS

The self-advocates identified a lack of information and accessible communication as key barriers for adolescent girls with intellectual disabilities to understand GBV and available

response services. Therefore, we asked self-advocates to provide recommendations to GBV responders on inclusive communication. Self-advocates recommended the following measures for GBV actors when communicating with adolescent girls and women like Samia (with intellectual disabilities):

- **Speak slowly, with a reassuring tone:** Use “a low voice, [speak] slowly, and repeat the explanation more than once. [If] she still doesn’t understand, you should ask her about which way you should talk so she can understand.”
- **Use active listening and show unconditional acceptance:** “The best thing is to not talk. Let her talk and you listen and be calm, so she knows that you are here to listen to her. You reassure her that you are here to help and not to judge or criticize.”
- **Show respect and support her understanding:** Talk to adolescents “directly” and support them to learn. “She should learn because she left school at a young age.” “This way you [service providers] empower her, and she becomes more confident.”
- **Create comfort:** “It should be a person from the same sex talking to survivors. You should know how to help her and the baby. You should sit with her and talk to her so she can be comfortable.”
- **Seek support when needed:** Bring someone adolescent girls are comfortable with and ask for this person’s support to help the adolescent girls understand and communicate.

RECOMMENDATIONS FOR GBV PROGRAMMING

While limited in scope, these consultations speak to the importance and urgency of creating access for women and adolescent girls with intellectual disabilities to access information about GBV, avenues for reporting, and opportunities for empowerment. To this end, organizations such as the IRC need to learn more about how to better meet the needs and uphold the rights of adolescent girls with intellectual disabilities, particularly on GBV issues. Humanitarian actors should start by developing their capacities to ensure the participation of adolescent girls with intellectual disabilities in GBV programming. This includes:

- Prioritizing the inclusion of adolescent girls and women with intellectual disabilities in GBV programming, including the accessibility of GBV prevention and responses activities and provision of reasonable accommodation.³

³ Reasonable accommodation is a strategy to guarantee equal access to services. It is a process that applies when, despite universal design, a person faces difficulties or specific barriers to access services or feedback mechanisms. Examples of reasonable accommodations include providing sign language interpretation or easy-to-read formats.

- Identifying the unique risks and barriers (physical, attitudinal, and information access barriers) that adolescent girls with intellectual disabilities face when it comes to accessing GBV information, prevention and psychosocial support programming, and response services.
- Addressing stigma and discrimination at the community level and raising awareness on the rights-based approach to disability (as opposed to the medical model or charity model).
- Recognizing and strengthening the capacities of adolescent girls with intellectual disabilities to identify and report GBV.
- Developing equitable and meaningful partnerships with local organizations and self-advocate networks that are known and trusted by adolescent girls with intellectual disabilities. Support their capacity to provide quality GBV prevention and response programming as part of the GBV referral pathway.
- Developing their capacities to implement a rights-based GBV response for adolescent girls and women with intellectual disabilities, including learning from and capacity-sharing with OPDs and self-advocates.

Annex 1: REFLECTIONS FROM IRC COUNTRY PROGRAM STAFF AND INCLUSION INTERNATIONAL

This section aims to complement the findings from self-advocates during the consultations with wider reflections on working with persons with disabilities from the IRC Lebanon country program team and Inclusion International.

IRC LEBANON

Based on their significant experience working with organizations of persons with disabilities (although not focused on intellectual disabilities), IRC Lebanon staff shared some of their reflections and recommendations:

- The formation of self-advocate groups is essential for understanding GBV risks and creating a support system for the prevention, response, and mitigation of GBV against women and girls with disabilities.
- Adolescent girls with disabilities experience risks that are similar to those experienced by other adolescent girls. Their inclusion in activities, such as those offered in a women and girls' safe space, should be prioritized.
- To that end, supervisors should discuss support for the inclusion of adolescent girls with disabilities with the facilitators of group activities, using universal design and reasonable accommodation to avoid excluding adolescent girls with intellectual disabilities. In addition to consulting with adolescent girls with disabilities, caregivers can play a role in answering questions and finding appropriate modes of communication, including the proper terminologies to use.
- All of this needs to be complemented by projects specifically designed for women and adolescent girls with disabilities.

INCLUSION INTERNATIONAL

Inclusion International's members around the world report that communities do not understand the barriers that women and adolescent girls with intellectual disabilities face. The stereotyping, labeling, and discrimination of women and adolescent girls with intellectual disabilities leads to their exclusion from education, Sexual and Reproductive Health and Rights (SRHR) services and GBV prevention programs and response services. Therefore, GBV practitioners should focus on addressing the following barriers in their activities:

- Lack of support and accessible information in GBV programming activities.
- Lack of the necessary knowledge or experience to support people with intellectual disabilities and their families by GBV actors.
- Lack of awareness-raising activities in GBV prevention activities to tackle the stigma around intellectual disability. The infantilization and stereotyping of people with intellectual disabilities as 'child-like', or incapable of learning by communities and in families, may also contribute to poor knowledge of sex and relationships, which can lead to unsafe sexual practices and a lack of awareness of abuse.
- Higher risks of violence including forced sterilization for women and girls with intellectual disabilities in places like institutions, or orphanages.
- Lack of meaningful and equitable partnerships with self-advocates and OPDs. The inclusion of women and adolescent girls with intellectual disabilities in development and emergency response programming, especially those focused on sexual and reproductive health and rights (SRHR) and GBV, is essential if these barriers are to be overcome. In order to be truly accessible and inclusive, it is important that international organizations like the IRC make sure that activities are planned in consultation with self-advocates and OPDs.

ADDITIONAL RESOURCES ON INTELLECTUAL DISABILITIES

Listen Include Respect is Inclusion International and Down Syndrome International's guidelines on how organizations can be more inclusive and accessible to people with intellectual disabilities and may be a useful resource for IRC partners.

Some other useful resources that Inclusion International members have worked on, and which can support the learning in this brief are:

- Inclusion Europe's - [Life After Violence](#) report
- Confe Mexico's - Course on [sexuality and rights for self-advocates](#)
- Mencap UK's - Page on [research into sexuality and relationships](#)
- Self-advocates Becoming Empowered (USA) Pages on [sexuality](#) and [abuse](#)
- KAIH's - page on [access to justice](#) with case study examples
- Liber and Plena Inclusion Spain- pages on [sexual](#) and [reproductive rights](#) of people with intellectual or developmental disabilities
- Asdown Colombia's - Report on [Body Autonomy](#) and [Learning about sexuality](#).

Annex 2 – SHORT STORIES AND QUESTIONS

STORY 1

Samia has an intellectual disability. She got married when she was 15 and left school.

She didn't want to get married but her parents told her she must. Now she is 17, has a baby, and is back at home with her parents.

Samia's marriage ended due to her husband hurting her. Samia's father blames her for bringing shame on the family.

STORY 2

Sara is a single woman who has a physical and intellectual disability. Sara has difficulty moving. She uses a wheelchair does not have a job.

One day a man comes to her and offers her help. She takes his food and money. After a week, he says that he will no longer help her unless she has sex with him. At that time, she has sex with him.

QUESTIONS:

1. Have you heard of something like this happening in your community?
2. What kinds of violence or harm do adolescent girls with disabilities face in your community?
3. If Sara told someone that she experienced this type of violence, how do you think people would respond?
4. Is there anything else you would like to share with us about this case study?