

BARRIERS TO INCLUSION OF PEOPLE WITH DISABILITIES AND OLDER PEOPLE IN GBV PROGRAMMES

TERMS USED:

OPDs: Organizations of persons with disabilities

OPAs: Older people's Associations

GBV: Gender based violence

FGD: Focus group discussion

KII: Key informant Interview

SDI: Social Development International

SBF: Syria Bright Future

FINDINGS

INTRODUCTION:

The results and recommendations presented in this document are the outcome of a research project conducted by a consortium of (SDI & SBF), supported by Elrha's Humanitarian Innovation Fund (HIF) programme. The aim of the project was to understand the barriers to inclusion faced by people with disabilities and older people in GBV humanitarian programming: including needs assessments, program design, implementation, and monitoring and evaluation.

The project was conducted in North West (NW) Syria, and some participants were from humanitarian workers living in southern Turkey who are involved in projects inside NW Syria. The project duration was one year.

Three local partners have participated and played a prominent role in this project. The partners are: Medad Humanitarian Foundation, Dar Al Salameh for older age people Care and the Association of Independent Syrian Kurds.

The original plan was to implement the activities of the project physically, but because of Covid-19, we had to complete the largest part of the project, especially individual meetings and FGDs, online. Therefore, the Covid-19 pandemic was one of the factors that directly influenced these two categories of the research.

Early on in our research, we realised that significant large-scale and systemic barriers to inclusion and extremely limited provision of GBV services exist in our context. Therefore, the focus of our research shifted away from the original aim to understanding barriers to GBV programming, towards understanding the wider contributing contextual factors and barriers that exist in this region and sector. We therefore propose that further research remains needed to understand specific barriers to GBV programming.

We hope that our findings can enrich the knowledge base about the life of the older people and people with disabilities in NW Syria, and help other actors build new approaches to be more inclusive, especially in GBV and general protection programming.

METHODOLOGY:

We started by conducting a quick primary survey to understand the general situation of people with disabilities and older people. We analysed the results to guide a snowball methodology in order to identify the most important sources of information.

We were able to reach the 3 main areas inside NW Syria; namely, Euphrates Shield, Afrin, and Idlib. By using a snowball method to target we were able to even reach some of the most marginalized groups. We drew on our networks and those of our three local partners.

The research included conducting 20 KIIs and 12 FGDs. Most of them were conducted online due to the Covid-19 pandemic.

The main characteristics of participants were:

In KIIs: 20 participants (12 men, 8 women)

- 9 older people.
- 8 humanitarian workers.
- 3 people with disability.

FGDS: 86 Participants (35 men, 51 women)

- 65 Humanitarian workers.
- 11 older people (5 of them are also caregivers for another older person or a person with disability)
- 1 caregiver of older people.
- 6 people with disabilities.
- caregivers of people with disabilities.

RESULTS:

CONTEXTUAL FACTORS:

These are the factors that either affect the lived experience of people with disabilities and older people, or affect the access and participation of the general population in GBV programmes. They can be seen as an outer circle of factors that create barriers to the inclusion of older people and people with disabilities' in GBV programmes.

These factors include:

- 1. Social/Environmental context: The general experience of people in extremely difficult economic conditions. In NW Syria,** economic conditions are poor as a result of instability and lack of resources because of multiple displacements and war. People with disabilities and older people can be disproportionately impacted by such conditions and less likely to have their basic rights met. An older woman said in individual interviews *"We are living in a major economic crisis under the incredible increase of prices and lack of income"*.
- 2. Institutional context: The corruption, real or perceived, of humanitarian organisations.** This belief that people with disabilities, older people and also some humanitarian workers have, has prevented people with disabilities, older people from seeking help from or engaging with organisations and service providers. And this belief, that they are unable to access and participate in the services available to them, is reinforced by the competitiveness of accessing limited resources. *"Frankly speaking, there is a gap between communities and organizations, and how civil society views it as a result of the accumulated processes of corruption,"* said one of the participants in individual interviews.
- 3. Institutional context: A lack of accountability and provision of services by some organisations.** For example, repeated data collection for needs assessments has raised expectations of communities in

general, and people with disabilities and older people in particular. This has resulted in them losing the trust in humanitarian organisations when services are not available.

4. One of the participants in FGDs mentioned: *“Every time the organizations come and take my data, and I didn’t benefit from any services, I no longer trust these organizations.”* **Institutional context: The general living experience of older people in discrimination against and negligence towards against them. Some people think that older people has "lived their life" . For example, the reduced care provision during Covid-19.** During the pandemic, the care for older people has declined. In particular, at the peaks of Covid-19 cases, priority was given to younger people in regards to access to beds and respirators; which are limited in number in NW Syria.

A participant in a focus group discussion said: *“Recently, in light of the Korona pandemic, priority is given to younger age groups over the older ones, as the priorities are decided depending on the limitations of medical services provided.”*

5. **Institutional context (GBV): The very limited provision of protection and GBV services.** Even when protection projects services are available, the lack of clarity about their roles and the services they provide for people also forms a barrier. Although this has improved over the years, this is still a barrier that prevents a considerable percentage of people from accessing these services.

An older participant mentioned in an individual interview: *“What are protection centers? I don’t know that they provide services suitable for my age. All I know is that they play with children”.*

6. **Social context/Attitude: The stigma surrounding GBV.** Stigma is still widespread in NW Syria and prevents beneficiaries from going to protection and GBV centers, even when people know about the services of these centers. This stigma is greater for people with disabilities and older people. And social and political reasons that led to the absence of protection services in some areas compared to others. This calls for better study and coordination for the distribution of protection centers.

A participant in the discussion sessions mentioned that in one case a father refused to allow their child to receive protection services, saying that he has no intention to destroy the future of his child as a result of the stigma that will be attached to the child if the child went to the protection center.

7. **Institutional context (GBV): Lack of satisfaction from beneficiaries of protection services including GBV.** One important reason is the lack of "concrete benefits" provided in those centers. In NW Syria in particular, two components of GBV programs are missing: providing shelters for survivors, and providing legal support. The main services available are limited to counseling and referral to health and relief services, but there is no capacity to actually protect those who fear repeated abuse. And

the misinterpretation of some religious beliefs and cultural misconceptions towards the protection centers and the services they provide, prevent some people from accessing such services.

A participant in an individual interview said: *“The centers are [only] doing half the work, which made the situation worse, as they are unable to prevent the recurrence of harm.”*

One of the participants, who works in the humanitarian field, says: *“protection centers do not properly define their real role in society in order to provide protection for vulnerable and marginalized groups, and if you asked people about their opinion about those centers, they would say that these centers are a joke and no real help is being provided”.*

8. Institution context: Lack of clear policies at humanitarian organizations for inclusion of people with disabilities and older people. When efforts are made to include them, they can do so incorrectly, and sometimes in a harmful way. For example, hiring persons with disabilities, but giving them trivial tasks or no tasks that relate to their position. So some people hire People with disabilities but do not follow up with their work, they do not evaluate their work, no penalties of rewards for their work. They employ them in any position so they can rationalize their salaries. Or some people using the inclusion of people with disabilities nominally without creating the atmosphere that empowers them for meaningful inclusion. All this affects the morale and self-esteem of people with disabilities and older people.

9. Institutional context: Lack of inclusion of people with disabilities and older people in general. **Limited** participation in the implementation and design of humanitarian projects in general, and projects related to them in particular.

An FGD participant mentioned: *“There is no real inclusion of people with disabilities in humanitarian work, as we are excluded based on preconceptions about our physical or health capabilities”.*

10. Institutional context: Short-term service provision. Recurrent displacement in NW Syria (especially before 2018) has affected access to services that may need long term follow up, like protection, health and psychosocial support. And the scarcity of stand-alone or integrated activities for people with disabilities and older people in humanitarian programs in comparison to the needs. This has also prevented people from participating meaningfully in designing, implementing and evaluating programs.

- 11. Social context: The role of extended families and tribes' relations.** Extended families and tribes can form a barrier to the provision of protection services or play a positive role in protecting more vulnerable community members. On one hand, it may prevent humanitarian workers from engaging in some protection cases where the perpetrator belongs to a notable family or a tribe to avoid any problems that may occur between the survivors' family or tribe and those of the perpetrators. On the other hand, families' and the tribes' leaders sometimes play a crucial role in protecting vulnerable people.
- 12. Institutional context: The poor application of localisation principles.** A lack of localisation is manifesting in restricting programming decisions to senior levels of NGOs and INGOs, which disempowers grassroots organisations and initiatives, who are part of and/or stand close to targeted populations. This important barrier compromises and prevents meaningful participation of targeted people.

DIRECT BARRIERS:

. Direct barriers can be seen as an inner-circle of factors that are specifically creating barriers for the inclusion of people with disabilities and older people in GBV programmes and services. These barriers can be divided into: attitudinal, environmental, institutional and other factors.

These barriers include:

A- FACTORS RELATED TO ATTITUDES AND CONVICTIONS:

1. People with disabilities, older people, and their caregivers, may not consider services such as protection, psychological support and other non-tangible services, as a priority need (unlike, for example food or other medical care) Many people with disabilities and older people, and their families, are experiencing severe economic hardship. Sometimes the basic needs of living are obtained through begging, and protection services may be viewed as a 'luxury'. (Links to Contextual Factors: 12)
2. Some care givers exploit or neglect older people and/or people with disability: One of the participants in FGD says that some families consider their children with disabilities a "source of livelihood." In one of the camps, two vans come every morning and take seven children with disabilities to be used while begging in the city and return them in the evening, and that is in agreement with the parent.

One of the participants says: “A while ago we were sitting with the forensic doctor of the city and he said that he was surprised by the death of an older age person and stayed for five days in his house and during this time no one knew that he was dead! knowing that his children live in the same city.

If there was someone who would take care of him and if he was not neglected this wouldn't have happened”. (Links to Contextual Factors: 10)

3. People with disabilities, older people and their caregivers have a negative perception about the quality of services in protection centers, and their ability to deal with difficult and complex cases. There is a perception, which is sometimes substantiated in reality, that protection and GBV programmes deal only with "easy" cases.

Many case managers during the workshops conducted in the scope of this project expressed this point by saying, “*We do not have sufficient experience to deal with difficult cases, as they need experts and specialists. Even during the trainings we received during our past years of work, we were not exposed to such [difficult or complex cases] cases and there was no discussion on how to act in the event of confronting such matters*”. (Links to Contextual Factors: 4 &6)

4. The negative perceptions held by staff of humanitarian organizations about the competencies of people with disabilities and older people. This leads to their exclusion from designing, implementing and evaluating GBV and protection programs. (Links to Contextual Factors: 7)
5. Some Caregiver's fear of sending those they care for to protection centers as they may be exposed to bullying or heightened risks as it is perceived that they are not able to defend themselves.

One of the participants in the discussion sessions said: “*I got married and had a deficiency and paralysis in one of my feet. And I got a male and 6 girls, and my son is often beaten because he is alone, and when I go out to him, I also get bullied... I am tired of this, my psychology and my children's psychology got tired, we are all tired*”. (Links to Contextual Factors: 5)

A MISCONCEPTION OF CAREGIVERS ABOUT THE CONSEQUENCES OF SENDING THEIR FAMILY MEMBERS TO PROTECTION CENTERS. SOME CAREGIVERS THINK THAT PROTECTION CENTERS MAY ENFORCE SOME OBLIGATIONS THAT THEY WILL NOT BE ABLE TO FULFILL. FOR EXAMPLE, OBLIGATION TO DO THINGS THAT REQUIRE EXTRA EXPENSES, LIKE BEING FORCED TO BUY CLOTHS TO THE CHILDREN, OR ASSISTIVE DEVICES ... ETC. MOREOVER, FEAR THAT THEIR

NEGLECT OR ABUSE OF PEOPLE WITH DISABILITIES AND OLDER PEOPLE IF THESE THINGS GOT UNCOVERED. **B- INSTITUTIONAL FACTORS:**

1. Lack of clear policies at organizations that work in protection and GBV in relation to the inclusion of people with disabilities and older people, which results in insufficient resources invested to ensure such inclusion. (Links to Contextual Factors: 7)
2. The costs (real or perceived) incurred in involving people with physical disabilities in implementing, monitoring and evaluating GBV projects activities, like the possible need for frequent travels in private transportation means for people with movement disabilities.
3. Lack of good advertisement about assistance that can provided to people with disabilities and older people that is related to protection and GBV programs. This is a big obstacle facing people with disabilities and older people who usually cannot access Centers easily, so they will not be motivated to visit centers without knowing beforehand about the assistance that can be provided to them in those centers.
4. Short term projects form a barrier in addressing the protection needs of people with disabilities and older people who may need long term care and follow up.

One of the participants, a worker with people with disabilities, in a KII said: *"Yes, we do have protection programs, but they are just to be shared on media because they lack sustainability. Programs or projects that lasts for several months only, don't meet the needs of these groups."*

C- ENVIRONMENTAL

1. The lack of suitable transportation or its high cost when available. There was a consensus among all type of participants that this is number one obstacle facing people with disabilities and older people from benefiting from GBV programs and other services. (Links to Contextual Factors: 1)
2. Public facilities and infrastructures are not accessible for people with disabilities and older people, such as lack of sidewalks in the street, lack of designated parking lots or bathrooms.
3. Lack of building adjustments for people with disabilities and older people in protection and GBV centers (the absence of a ramp or an elevator). This is because of lack of management awareness of the importance of such adjustments, or lack of budget.

4. Lack of protection staff who have skills in sign language interpretation to facilitate communication with beneficiaries with hearing impairment, which makes them depend on a family member or a neighbor. This can deprive people with hearing disabilities of privacy while receiving assistance.

D- OTHER BARRIERS:

1. The limited number of INGOs and local NGOs that advocate for the rights of people with disabilities and older people. People with disabilities and older people needs advocacy, training, resources, so if only few INGOs/NGOs advocates for this, that means having a context that is less motivated for their inclusion. Consequently, a fewer number of organisations will think about the inclusion of people with disabilities and older people.
2. People with disabilities and older people may not be able to afford smart phones, and thus are often not able to participate in online needs assessments or monitoring & evaluation activities. e perpetrators of violence against people with disabilities and older people can be caregivers themselves. This can mean that the survivor is unable to seek help and may resort to isolation, especially in the absence of alternative care providers. The violence by the caregiver may be a result of psychological burnout from caring responsibilities.

One of the participants in FGD said: *When a psychosocial supporter met a woman during her field visits, the woman's brother suddenly entered the room and looked at her strangely. After that, the woman began describing her life as if she was living in "heaven". And after the brother left the house, the lady was able to tell the truth and expressed her brother's mistreatment of one of her kids but she can't do anything about it.*

3. The disruption of the social fabric and diminished role of positive societal norms and traditions, as a result of conflict and displacement, has increased the violence against people with disabilities and older people.

A humanitarian worker told the story of a thirty-year-old girl with an intellectual disability whose parents died and was left without any care from relatives or the society. She was repeatedly abused without the perpetrators being found or prosecuted. So, in the previous example, the girl would have probably received protection from her family or social surrounding if they existed.

4. The lack of visibility of representative organisations (OPDs and OPAs) means they are unable to participate in designing, implementing and evaluating GBV programmes. It was shocking that only a very small number from more than one hundred humanitarian workers who participated in the workshops were able to name an OPA or OPD in the communities where they operate.

INTERSECTIONALITY

In our research, we intended to understand the intersection of older age and disability on the one hand, and the intersection of older age or disability with other identity characteristics on the other hand (such as gender, race, language and political tendencies). We identified several reflections that can be summarised as follows:

1. Barriers to accessing or participating in the services of protection against GBV are greater for women with disabilities and older women than for men with disabilities and older men. Women generally experience additional social and religious restrictions that limit their freedom of movement and access to service centers.

One of the protection workers who participated in the focus group discussion said: *“All cases of disabilities are difficult, but females with disabilities remains more difficult because as you know, we are living in a conservative society”*.

2. Older persons with disabilities experience greater economic and social barriers compared to older persons without disabilities. People with disabilities may fear getting older and older people may fear having disability while aging and relying on their caregivers to carry out their daily tasks.

One person with a disability participating in individual interviews expressed his fear of getting older as his brother, the caregiver, tells him harsh words such as, *“When will you die! so that I will be relieved of the trouble of taking care of you”*

3. Camp residents are more vulnerable to stigma than residents of urban communities such as cities and towns because of the lack of privacy as a result of the housing situation in the camps or the fact that the centers are exposed where the person is unable to move easily. This creates an additional challenge for them to go to protection centers and obtain their services.
4. Internally-displaced people with disabilities and older people experience poorer economic and social conditions compared to those in host communities, as host communities have greater opportunities to adapt and access services, including the services of protection against gender-based violence. One person with a disability participating in individual interviews said: *“Displacement destroys people with a disability. When I was in my original city, I had a suitable job*

for my disability, close to home and suitable for me. But now, I have to worry about securing my livelihood". (Links to Contextual Factors: 1)

5. People with intellectual disabilities and severe physical disabilities have fewer opportunities to access or participate in the services of protection against GBV compared to people with mobility disabilities, as the inclusion of these disabilities can require the involvement of caregivers and families and/or extra expenses. Those leading such services may only take a nominal and tokenistic approach to inclusion of these groups. One of the individual interviewees with a disability said: *"Mild physical disabilities cannot be marginalized as long as he is able to claim his rights. But severe mental or physical disabilities are marginalized and there is no one to pay attention to them"*.
6. People with disabilities relating to military service are less likely to receive protection services compared to people with disabilities of non-war origin, as a result of the unwillingness of many service providers to engage with persons with a previous military affiliation out of fear of being stigmatised with terrorism.

CONCLUSIONS AND RECOMMENDATIONS:

The research team has identified the following conclusions and recommendations in response to the research findings:

1. Researching sensitive and complex issues, in difficult contexts needs a high level flexibility in designing and planning the project. For example, we found that political factors intervene in the implementation of services sometimes, but people didn't wish to speak up about this issue. Also, the security situation can change suddenly and dramatically which affects the implementation of the research.
2. There are multiple factors and barriers that people with disabilities and older people face in GBV programming. These factors are interconnected, which makes overcoming them a challenging task that needs long-term strategies.
3. When we want to enhance the inclusion of people with disabilities and older people in GBV programs, we shouldn't only think about combating the specific factors and barriers that affect individual inclusion, but also about possible contextual factors and barriers that relates to the general lived experience of people with disabilities and older people. It may be more cost-effective to address these wider barriers and factors in the longer-term.

4. There is a large and unexplored potential for OPDs and OPAs to contribute in eliminating barriers of inclusion in humanitarian response in general, and in GBV programs in particular. Therefore, the establishment empowerment, and networking of OPDs and OPAs should be a priority. This would also adhere to humanitarian principles and existing inclusion guidelines.
5. When we want to enhance the inclusion of people with disabilities in GBV programs, we shouldn't only take into consideration the special needs of inclusion of people with movement disabilities, as organisations have started to take their needs into consideration, but also the special needs of inclusion of people with verbal, hearing and visual impairment should be taking into consideration, like the provision of sign language interpretation and Braille writing.