



We are Able!

Policy Brief: Perceptions, Capacity & Law





Index

1. Scoping Studies summary of findings.....	3
2. Introduction	4
3. Background and methodology	4
4. Intervention rationales behind WaA! Theory of Change and how these relate to the experiences of persons with disabilities.....	10
5. Issues for further consideration, study and reflection in the WaA! learning agenda	11

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1. Scoping Studies summary of findings

1. Stigmatization and lack of awareness on rights, laws and opportunities drive exclusion of persons with disabilities. Combined with a lack of reliable data, this could undermine the efforts to promote inclusive practices, interventions and policies on food and nutrition security.
2. Lack of institutional capacity and clear theories of change – notably on how to create access to decision making – common among local implementing partners and Organizations for Persons with Disabilities (OPDs), which could influence the intended impact of the We are Able! (WaA!) programme. Addressing this gap presents a critical intervention pathway to achieve sustainable change.
3. Good laws exist, but “bad” implementation persists in all target countries. Across the WaA! countries, numerous laws and policies on disability inclusion already exist on paper; the focus should now be on understanding and “filling” the implementation gap.



2. Introduction

How can practitioners of the WaA! programme work with Persons with Disabilities (PWD), civil society organizations and OPDs, as well as local authorities in order to co-create inclusive governance for access to basic resources that leaves no one behind? They can start by exploring the different notions, assumptions, and theories of change that guide their intervention strategies and practices. Such an exploration provides a better understanding of the extent to which these interventions correspond to the concerns and challenges of persons with disabilities on the ground. Such a better understanding, in turn, may enhance efforts to promote inclusion of persons with disabilities within WaA! programme.



3. Background and methodology

The WaA! programme is funded by the Dutch Ministry of Foreign Affairs as part of the Power of Voices Partnerships for Strengthening Civil Society and aims to contribute to inclusion of persons with disabilities and other marginalized groups to increase their access to food and basic services (e.g., access to agricultural extension, techniques, inputs, markets; resource administration and dispute



resolution) and resources (such as land and water) for food production. Inclusion also comprises economic and physical access to available food in both relief (distributions) and recovery settings. The programme combines capacity strengthening interventions and social accountability processes with a local inclusive agenda assessment score for local authorities. This should stimulate change in practices and laws for sustainable inclusion of persons with disabilities.

The conclusions in this policy brief are based on Scoping Studies, reflections during the regional Knowledge Sharing workshop in Nairobi, and studies validation workshops at country level in light of evidence collected in DRC, Ethiopia and Uganda in the period June – October 2021.

3.1 Stigmatization and lack of awareness creating barriers to access to resources and services

3.1.1 Perceptions and mindset

Generally, access to services and resources for persons with disabilities is conditioned by (mis)conceptions and **stigmatization** practices in the communities.

- In Uganda, perceptions of persons with disabilities are mostly influenced by the disability they have; not by what they can do. Such perceptions influence rights, i.e., women with disabilities are denied inheritance rights to land and property, because society still sees persons with disabilities as outcasts. This is evidenced by the demeaning names used to address them, like 'half human being', or 'good for nothing'. This 'othering' is experienced from early age, fueling stigmatization and exclusion of persons with disabilities as an early age as one interviewee recounted:

"When a person of short stature gave birth, almost the entire staff of the health centre gathered, including doctors and other patients, and they were laughing and waiting to see what kind of baby she was going to deliver".

An interviewee living with disability encountered how the midwife at the local maternity center where she came to deliver responded to her, when the bed was inaccessible to her, "**you mean you cannot climb the bed to deliver your baby; how did you get the pregnancy?**".

- In Democratic Republic of Congo (DRC), visual and hearing impairment, as well as physical disability are perceived as a curse or a sign of bad fate for the family. Persons with disabilities are considered as "God's temptation" and "punishment for bad deeds committed" by the family. Persons with disabilities are seen as vulnerable and useless, or as beggars. Such perceptions and mindset lead to domestic, administrative, and societal violence, and result in unequal access to resources and services. To illustrate administrative violence, one interviewee narrated:



“Most of the time, receptionists don’t allow us to meet authorities when we ask for an audience. They assume we are there to beg, to disturb. They even don’t allow some of us to access the office. Sometimes, we need to be accompanied by a person without disability and of a certain social standing to be taken seriously and get access to services in the public administration”.

- In Ethiopia, the widely accepted notion that ‘disability is a curse’ is generally disappearing, yet still tends to persist in rural communities. Several interviewees including persons affected by leprosy and from the government indicated that many families in their target areas do not want their children with disability leave the home to demand their rights. They don’t want their children to be seen in public, because they believe or experience that society still believes that disability is a curse.
- Moreover, the scoping studies also observed existence of discrimination among persons with disabilities based on types of disability, social status, position in society was. As one representative from an organization for persons with disabilities in DRC noted:

“Those among the persons with disabilities that have succeeded in their careers or always have their projects funded develop a kind of discrimination towards more vulnerable persons with disabilities...they consider themselves as different from the others. Some don’t even fight for persons with disabilities rights, although they belong to that category”.

- It was however noted that discrimination or marginalization decreases when persons with disabilities set an example, by their success in lobby or activism, politics, or business. Examples include a man with visual impairment being in charge of a huge NGO in Bukavu, and another person living with albino and working with a UN agency. These successful individuals were cited to have gained huge respect in society.

3.1.2 Awareness

Lack of awareness among persons with disabilities and target communities is seen as a serious obstacle to exercise their rights, and to assure access to services and resources. While awareness on the rights of persons with disabilities seems to be increasing in Ethiopia, especially in rural areas it remains low. Practices of labelling persons with disabilities as “bad luck”, “useless”, “beggars” or a “curse” in Uganda and DRC can be attributed to such lack of awareness.

In all cases, legal frameworks exist that acknowledge the rights of persons with disability. Awareness raising on relevant legal provisions and disability rights is key in enhancing practitioners’ and decision makers’ understanding of their mandates and responsibilities in terms of inclusive service delivery. “Targeted awareness raising” could address stigmatization and stereotypes at different levels. Examples of targeted awareness raising include focusing on leaders of faith-based organizations, considering that they may be able to promote inclusion by using their spiritual platforms and acting as positive role models; or local authorities who are responsible for particular thematic areas.



3.1.3 Livelihood access

Stigmatization and discrimination directly result in exclusion from services or livelihood opportunities, as an interviewee in Uganda explained during a focus group discussion:

“I was invited for an interview as a Community Development Officer and one of the requirements was the ability to ride a motorcycle. When I appeared for the interview in a wheelchair, I was asked how I was going to ride to the field every day... I failed to get the job, although I was told that I was the best candidate. When I did not get the job, my father insulted me, telling me that I was wasting my time; and that no one would give me a job after wasting his money on school fees”.

Research unveiled the tendency of NGOs not to recruit persons with disabilities, considering them as a potential burden. Persons with disabilities are often not informed about (formal) job opportunities, or not considered as job seekers at all, as an interviewee from DRC explained, **“People might inform us about charity activities where we might get something (food, clothes...), but almost never share job advertisements or opportunities”**. Often, persons with disabilities **are overlooked as a marginalized group**. For instance in a programme to provide agricultural inputs in northern Uganda, they were left out because they were considered **inactive in agriculture**.

3.1.4 Reasonable accommodation

To some extent, **challenges in physical access** (public buildings and roads) **and lack of assistive devices** limit access to services and resources for persons with physical disabilities. Independent movement of persons with disabilities is obstructed by lack of ramps or elevators, handrails, grab bars and tactile markings at staircase ends in public buildings; or lack of ramps, wheelchairs, crutches or hearing aids in schools. Absence of such necessary assistive devices leads to exclusion from participation in community activities and education. Even when district agricultural offices, hospitals or courts of law have ramps, there are no sign language interpreters, which makes these services inaccessible for persons with disabilities.

3.1.5 Limited data available on disabilities

Overall, the scoping study found that there remains a lack of reliable data, and structural failure to fill this gap. Organizations try to gather data at project level to fill the gap, but unfortunately they lack proper data management systems. As a result, little is known about the actual numbers of persons with disabilities. The absence of reliable data was observed to have resulted in some persons with disabilities benefitted from several projects, while others were left out. Limited data may undermine efforts for including persons with disabilities. How WaA! might fill this gap deserves further consideration. In future data collection, shared local understanding of who is considered as a person with disability is important, as well as of the particular vulnerabilities associated with different forms of disability. Labels that might further lead to exclusion should be avoided in data collection.



3.2 Lack of institutional capacity and clear theories of change among OPDs

The Scoping Studies brought out various challenges around the organizations representing persons with disabilities. Generally, the majority of civil society organizations in the Scoping Study countries focus on malnutrition, poverty, agriculture and livestock, or peacebuilding, and have only limited interest in persons with disabilities. Even those that integrate human rights in their missions, do not visibly take the rights of persons with disabilities into account. The civil society organizations that consider “inclusion” of persons with disabilities as their ‘main mission’ were reportedly primarily driven by increasing prospects to access donor funding.

Very few CSOs exist that are managed by and dedicated to persons with disabilities. Those that exist lack institutional capacity, experience and resources, while there is limited donor interest in organizations focusing on disability. In several instances in DRC, among persons with disabilities, perceptions of OPDs are not positive, with OPD leaders allegedly profiteering from funds acquired on behalf of other persons with disabilities. In Uganda, on the other hand, the study established that an increasing number of CSOs provide services to persons with disabilities, as a result of increasing funding for such programmes.

Public authorities are hardly aware of the work of these OPDs, and hence government support is limited. And when they are aware, they tend to consider them as organizations that ‘assist’ and ‘care for’ persons with disabilities, rather than ‘representing’ persons with disabilities. Likewise, faith-based organizations consider persons with disabilities as vulnerable people that need charity, but not as a group that holds rights to actively participate in decision-making on issues that concern their lives. This results in widely shared feelings of disappointment and anger among persons with disabilities, as two interviewees explained:

“What bothers me is that we are continuously considered as people that need charity, help or assistance; even when many of us have capacities to do things, to think and participate in changing our society. They look at us not as a human resource, but as a person to help. This is unacceptable and must change”.

“Why don’t people accept that we have the same rights as all Congolese? All we need is that our condition is not used as an excuse to discriminate against us and ignore our rights... NGOs, churches and other institutions that care about us do a good job, but they should go further, and fight with us for a society in which we are accepted as human beings with human rights”.

Reportedly, some OPDs – and especially those established only recently – lack capacity to design and implement lobby and advocacy strategies. Some also lack proper governing structures and legal



documents; proper office space with basic amenities such as toilets or water, office furniture; or their locations are inaccessible for persons with disabilities.

While several governmental and non-governmental institutions have interventions focusing on OPDs, coordination is lacking. This results in a patchwork of interventions, limited exchange of experiences, and missed opportunities for synergy.

3.3 Good laws, “bad” implementation

While **national policies** and **legislative frameworks** to promote the rights of persons with disabilities exist in the three countries in which the scoping studies were conducted, exclusion from access to services and resources also results from lack of implementation of existing laws. Moreover, awareness of these laws by the persons with disabilities, the community and sometimes the local authorities themselves is generally lacking. For instance, persons with disabilities in Uganda were unaware about a special Covid relief grant for persons with disabilities announced during the lockdown in June 2021.

Yet, the problem is not only one of limited awareness: negative experiences with discrimination and exclusion influence persons with disabilities motivation to seek for services and resources, even when laws are known. This is often interpreted to mean that persons with disabilities have “low self-esteem”. In all cases, local authorities lack a comprehensive action plan to implement existing laws and policies that might promote inclusion and prevent discrimination of persons with disabilities. Limited accountability by public authorities at local and national level on the inclusiveness and responsiveness of the services rendered was also highlighted as a symptom of bad implementation of existing legislation.



4. Intervention rationales behind WaA! Theory of Change and how these relate to the experiences of persons with disabilities

Generally, among the WaA! Partners, the scoping studies identified the following hypotheses that guide their interventions, and which also match with the assumptions guiding the WaA! Theory of change:

1. Empowerment of persons with disabilities and their inclusion in national, provincial and local institutions is essential for social integration and the promotion of their dignity
2. Promoting the rights of persons with disabilities requires awareness raising, promoting positive role models, and changing narratives that legitimize their exclusion in decision making and in access to natural resources and services, and limit their food and nutrition security.
3. Gender-sensitive approaches are critical in addressing exclusionary practices, beliefs, and social norms that limit access to resources and food security
4. Public Authorities play a pivotal role in the promotion and localization of inclusive service delivery and development agenda.
5. Strengthening the capacity of OPDs is vital in empowering their mandate to articulate the rights of persons with disabilities and design effective Lobby and advocacy strategies.



5. Issues for further consideration, study and reflection in the WaA! learning agenda

Generally, these hypotheses were underwritten by the diverse stakeholders participating in the scoping studies. Nonetheless, critical reflection of persons with disabilities on their own experiences, as well as preliminary experiences with implementation of the WaA! programme brings out a number of issues that deserve further consideration, study and reflection in the continuation of the programme.

1. From the Scoping Studies, it became clear that many partners in the WaA! programme consider **awareness raising about rights** among persons with disabilities as a key component of the programme. There is therefore a need to further investigate **what awareness raising means contextually, for instance, promoting rights to services and resources, or rather promoting participation in decision taking? It is also important to investigate whose awareness needs to be raised, as well as** the possibilities of **'targeted awareness raising'** i.e. focusing on leaders of faith based organizations who can address specific topics related to inclusion or, specific local authority responsible for particular subjects.
2. Stigmatization emerged as a central theme from the studies. Being a broad concept with contextual nuances, **how to change social norms leading to stigmatization in specific communities** remains a central concern for the programme, and a key area for further study. Analysis of how WaA! and like-minded programmes can effectively synergize efforts to change social norms is thus recommended. Furthermore, WaA! partners should be concerned about and investigate how to eliminate potential stigmatization within their own intervention practices.
3. **Access to basic social services** – notably education and health care – is seen as essential for decreasing vulnerability and exclusion. A common understanding of what **accessibility** entails is required among persons with disabilities, government authorities, and the community. Understanding of accessibility should include physical access and making buildings accessible and user friendly. This also applies to the office facilities used by WaA! partners themselves, the majority of which are hardly accessible. But accessibility entails more: there is a need to further investigate how to create access to decision-taking, including overcoming limited awareness and negative attitudes towards participation of persons with disabilities.
4. While OPDs claim to promote empowerment and access to decision-taking, this is often not translated into intervention strategies. Efforts for inclusive decision-taking do not by definition combine easily with the promotion of economic wellbeing, employment creation, or removing barriers to accessing labor markets. Each of these interventions require different types of expertise and strategies. How to **strengthen the capacity of OPDs in designing effective advocacy strategies and clear theories of change and effectively communicating with Local authorities**, is an area that requires further attention

for the WaA! programme. Furthermore, in the empowerment of OPDs, their legitimacy among the people they represent should be a central concern.

5. All Scoping Studies highlighted the existence of national legislation to protect and promote the rights of persons with disabilities. Yet, implementation is either weak or lacking. Barriers towards implementation of the existing legal frameworks need to be investigated, as well as strategies to assure that **existing legislation is respected and realized in practices**.
6. Overall, the Scoping Studies observed a lack of reliable data, which undermines effective efforts for inclusion of persons with disabilities. **Better data collection** requires shared understanding of different categories of disability, and the particular vulnerabilities associated with these, while preventing that labels and criteria used further exclusion.

