



Inclusive Futures

Promoting disability inclusion



Applying CRPD standards to programmatic processes: A look at inclusive programming in practice

A technical paper by the International Disability Alliance

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The paper has greatly benefited from the work that went behind the drafting of the recently released [Global Disability Summit Discussion Paper on OPD Participation](#), which has been extensively cited here.

In addition, this paper is informed by the discussions on inclusive programming at the [Learning & Exchange Workshop on Inclusive Employment and Inclusive Programming](#) held in Kenya in May 2022, which had participants from within and outside the Inclusion Works program. The writing of the paper was guided by the IDA Inclusive Livelihoods Task Team and was led by the IDA Secretariat, supported by Nishtha Vashistha and OPD Engagement Officers of IDA and the African Disability Forum (ADF). IDA is also thankful to the Inclusion Works Program Management Unit (PMU) for their support in providing feedback to the draft. Last but not least, we are grateful to the OPDs, INGOs, and other partners who participated in our discussions and provided us with their perspectives and experiences on inclusive programming.

The paper draws heavily from IDA's experiences within the Inclusion Works program. However, it is not an evaluation or critique of how the consortium or consortium partners undertook inclusive programming and meaningful engagement of persons with disabilities. The paper looks at some of the challenges and solutions to inclusive programming in the context of IDA's experiences within Inclusion Works and draws recommendations and practical guidance from this to inform the growing discourse on CRPD-based inclusive programming.

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GLOSSARY

ADF	African Disability Forum
CDRA	Caucus on Disability Rights Advocacy
CIG	Country Implementation Group
CRPD	Convention on the Rights of Persons with Disabilities
FGDs	Focus Group Discussions
FCDO	Foreign, Commonwealth and Development Office, UK Government
GDS	Global Disability Summit
IASC	Inter-Agency Standing Committee
IDA	International Disability Alliance
II	Inclusion International
IFHOH	International Federation of Hard of Hearing People
INGO	International Non-Governmental Organization
IW	Inclusion Works
KII	Key Informant Interview
MEL	Monitoring, Evaluation and Learning
NOAC	National OPD Advisory Committee
NPAC	National Programme Advisory Committee
OPD	Organization of Persons with Disabilities
PMU	Program Management Unit
RSH	Resource and Support Hub
SDGs	Sustainable Development Goals
UDPK	United Disabled Persons of Kenya
UN	United Nations
UNDIS	UN Disability Inclusion Strategy
WBU	World Blind Union
WFD	World Federation of the Deaf
WHO	World Health Organization

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1. Introduction

1.1 About the Inclusion Works project

In July 2018, at the Global Disability Summit (GDS) in London, the Government of the United Kingdom announced a new innovative UK Aid Connect program that would support persons with disabilities in accessing jobs in the labor market in global South countries.¹ One component of this funding was to be led by a consortium of eleven organizations, of which International Disability Alliance (IDA) was a part, called the Inclusion Works (IW) program. This program takes a rights-based approach to improving the representation of people with disabilities in formal employment. The program falls under the Inclusive Futures umbrella², a multi-partner inclusion initiative working to pilot innovative approaches to improving access to work, education and healthcare for people with disabilities, as well as to tackle stigma and discrimination.

The Inclusion Works program set itself the challenge of **demonstrating how to accelerate the realization of the right of persons with disabilities to employment**, to overcome the substantial underrepresentation of persons with disabilities in formal employment. Cutting away from typical approaches that have been looking at “putting people into jobs,” IW focused on system-level changes and worked to transform practices through four main pathways:

1. Influencing legislative and policy interventions – Governments increasingly ensure implementation of CRPD-compliant employment legislation and policy, and facilitate incentives for inclusive employment
2. Building the employment readiness of jobseekers – Women and men with disabilities take active part in employment and income generation opportunities
3. Building disability inclusion among employers – Individual employers (private, public and third sector) have more inclusive practice which aligns to CRPD Article 27
4. Building the capacity of supporting functions in the labor market to hold the system accountable – National and local OPDs and other civil society organizations (CSOs) have the structures and capacity to engage and support women and men with disabilities and the private sector in developing inclusive practice

To support the objective of enhanced inclusion of persons with disabilities in formal employment as a key dimension of participation and inclusion in society, IW also sought to adopt rights-based, participatory methodologies. The assumption was that there can be no disability-inclusive development

1 Department for International Development and The Rt Hon Penny Mordaunt MP, “UK calls for action to address ‘global injustice’ of discrimination against disabled people.”

2 Inclusive Futures, inclusivefutures.org.

without persons with disabilities centrally guiding the work, through OPDs as their representative organizations. In this direction, IW worked with OPDs as partners with a unique mandate to represent and advocate for persons with disabilities, with an intention to ensure meaningful OPD participation throughout programming.

CRPD-based inclusive programming is programming that proactively seeks to understand and explore the implications and responsibility of a project or program to advance the rights of persons with disabilities. In line with Articles 4.3 and 32 of the CRPD, it entails ensuring meaningful engagement of OPDs across the project cycle, from design stage to budgeting, from implementation to monitoring and evaluating project impact.

However, what “meaningful OPD participation” meant, and how it was to be operationalized through inclusive programming, was not understood the same way by all consortium partners. IW brought together INGOs, OPDs, academic partners and employers who had no or limited prior experience of collaboration and diverse experiences. This is how the journey began.

At the onset of the project, it became clear very quickly that OPDs had higher expectations than what the project design actually had covered for. Risks of tokenistic roles were flagged early on. As an example, country design workshops where the IW Theory of Change was reviewed and adapted to each country context were organized with very limited participation. Four years later, as the IW project concluded, a learning and exchange workshop organized under the project was entirely led by OPDs, mobilizing employers and technical partners as complementary allies – both from within and outside the consortium. A major shift has happened in how the IW consortium evolved and embraced OPD participation.

This paper is informed by this journey of OPDs progressively negotiating a more meaningful place at the decision-making table, and partners transforming their ways of working and the roles typically assigned to OPDs. It is complemented by learning and recommendations around meaningful OPD engagement that IDA and its allies engaged in during the past few years, in particular through the Global Action on Disability (GLAD) network and the 2nd Global Disability Summit 2022.

This paper is addressed to development and humanitarian practitioners, international organizations, OPDs, and donors. It wishes to **demonstrate how CRPD standards and meaningful OPD participation can be actualized across all stages of the project cycle as a core component of rights-based disability-inclusive practices**. Some of the questions that this paper seeks to address include:

- What is the jurisprudence available around meaningful OPD engagement (Articles 4.3 and 33.3 of the CRPD)?³
- What are some of the challenges and opportunities in implementing CRPD-based inclusive programming?
- What examples exist from within the IW program on meaningful engagement of persons with disabilities, including for those from underrepresented groups?⁴
- What does inclusive programming look like in the context of the project cycle?

1.2 Methodology and scope of the paper

This paper has been developed by the IDA Secretariat with inputs from the IDA Inclusive Livelihoods Task Team, comprising African Disability Forum (ADF), Down Syndrome International (DSi), Inclusion International (II), International Federation of Hard of Hearing People (IFHOH), World Blind Union (WBU) and the World Federation of the Deaf (WFD).

It utilizes mixed research methods to compile the experiences of inclusive programming and meaningful engagement of OPDs, primarily from the Inclusion Works program, in the larger context of CRPD-based inclusive development, particularly Articles 4.3, 32 and 33.3. This includes review of existing literature on meaningful engagement of persons with disabilities, key informant interviews (KIIs) with INGO partners in the program countries and those at the global level, and online focus group discussions (FGDs) with IW OPDs in the four countries (see Annex A for details). This was done to gain an insight into the challenges and opportunities that exist for all.

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- 3 The CRPD enshrines the obligation of states parties to closely consult and actively involve persons with disabilities (Art. 4 (3)) and the participation of persons with disabilities in the monitoring process (Art. 33 (3)).
 - 4 According to IDA, underrepresented groups are those among persons with disabilities who enjoy less visibility in decision making processes. The disability movement, like other social movements, is not homogenous. There are some groups that have traditionally been less included in participatory processes, or harder to reach, or that face higher barriers to participation, such as persons who are deafblind, persons with intellectual disabilities, persons with psychosocial disabilities, autistic persons, deaf people. It can also include those who may be less engaged in decision making such as women, children, older people and indigenous persons, as well as people from diverse faith, ethnicity, caste, class, sexual orientation or gender identity minorities. This understanding may differ in different countries, cultures and contexts.

The paper also draws from the [GDS Discussion Paper on OPD Engagement](#) developed in the run-up to the 2nd Global Disability Summit 2022, with contributions from members of the GLAD network.⁵

Finally, the paper is largely informed by the experiences of the OPD Engagement Officers in their role within IW and by documents prepared by the IDA Inclusive Livelihoods Task Team, as well as the discussions from the Learning & Exchange Workshop on Inclusive Employment and Inclusive Programming held in Kenya in May 2022.

The paper is not an in-depth presentation of the full scope of inclusive programming; rather, it gives an overview of challenges and opportunities in inclusive programming, focusing on the four participating countries of Inclusion Works and the reflections from the program. The paper is not an evaluation of the project, its implementation or its partners. It presents the key challenges and possible solutions to CRPD-based inclusive programming, which were shared by the different stakeholders engaged in this program and beyond the consortium as well. In many cases during the FGDs, the participants not only drew from the IW program but also reflected on their larger experience in the disability-inclusive development. The participants at the Learning and Exchange Workshop in Kenya included participants from outside the Inclusive Futures consortium, and the experiences shared by them have also informed the paper, including the recommendations.

⁵ GDS Discussion Paper, Promoting engagement of organizations of persons with disabilities in development and Humanitarian Action

2. Inclusive Programming: A Process for Ensuring Meaningful OPD Engagement in Policies and Programs

2.1 The long journey towards recognizing participation of persons with disabilities

Persons with disabilities are among the most excluded

Although persons with disabilities make up 15 percent of the world's population, they are one of the most marginalized population groups and are overrepresented among the poorest people in the world.⁶ They are less likely to access basic services and enjoy their human rights.⁷ Available data shows that people with disabilities are less likely to participate in the labor force, with almost two-thirds of those who are of working age being outside the labor force. If actually employed, people with disabilities are less likely to have paid jobs.⁸ Discrimination in access to services and enjoyment of human rights is experienced even more acutely by underrepresented groups of persons with disabilities, such as persons who are deafblind, persons with intellectual disabilities and persons with psychosocial disabilities, but also women, children or indigenous people with disabilities.

Stigma and prejudice result in decisions being made on their behalf

Over the years, the understanding of disability has evolved from a charity and medical model to a social and human rights model. Under the charity and medical model, persons with disabilities were considered objects of pity, or people with impairments to be fixed, with no or limited consideration for their opinion or capacity to decide for themselves. The social and human rights model looks at the barriers in the environment and is based on the principle "Nothing about us without us."

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- 6 The WHO World report on disability states that one in five of the world's poorest have a disability.
- 7 Compared to children without disabilities, children with disabilities are 25% less likely to attend early childhood education, 16% less likely to read or be read to at home, and 49% more likely to have never attended school. UNICEF. "Seen, counted, included."
- 8 Stoevska, "International Day of Persons with Disabilities."

However, unlike other social movements, for example women’s rights movements that are led by women leaders, the leadership of persons with disabilities on advancing inclusion of persons with disabilities is lagging far behind. For persons with intellectual disabilities and persons with psychosocial disabilities, the prospects of participation in decision-making are even more limited as their legal capacity continues to be largely denied.

A shift in paradigm with the Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities (CRPD) legally anchored the rights-based approach to disability, and reaffirms the economic, social, cultural, and civil and political rights of persons with disabilities. Influenced by the active participation of persons with disabilities in the drafting of the text, the CRPD recalls that **the full and effective participation of persons with disabilities is central to the realization of their human rights and inclusion of all persons with disabilities in society.**

Echoing the motto “Nothing about us without us,” it explicitly lays down the obligation to meaningfully include all persons with disabilities in all issues affecting their lives, through their representative organizations. This is recalled in the purpose of the Convention (Article 1), as a general principle (Article 3), as a general obligation (Article 4.3) and as a cross-cutting issue under specific rights, such as the right to participate in political and public life.⁹

Article 4.3 of the CRPD states:

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

Article 32 further states that all international cooperation, including international development programs, should be inclusive of and accessible to persons with disabilities.¹⁰

Article 33 also notes that civil society, in particular persons with disabilities and their representative organizations, shall be involved and participate fully in the monitoring process.¹¹

⁹ GDS Discussion Paper, Promoting engagement of organizations of persons with disabilities in development and Humanitarian Action

¹⁰ UNDESA, Convention on the Rights of Persons with Disabilities (CRPD).

¹¹ UNDESA, CRPD.

In addition, Article 11 also places responsibilities on all humanitarian and development agencies to be inclusive of persons with disabilities.

Participation as a process is a legal obligation that supports participation and inclusion as an outcome

The Universal Declaration of Human Rights states that “every person has the right to take part in the government of his or her country, directly or through chosen representatives, and the right to equal access to public service.” However, with the CRPD, participation takes a new scope and purpose. It enshrines participation as a general obligation for states.¹² The CRPD values and recognizes participation as both a process and an outcome. As a process, participation of persons with disabilities in decision-making supports the realization of the full and effective participation and inclusion as a desired outcome.¹³ The CRPD Committee recognizes that there is a positive impact on decision-making processes when persons with disabilities participate and bring to the table the value of lived experiences.

Unique role of Organizations of Persons with Disabilities (OPDs) as representative organizations

The CRPD sets a unique role for OPDs as key intermediaries to represent and channel the views and perspectives of persons with disabilities. Distinct from organizations *for* persons with disabilities, organizations *of* persons with disabilities are a specific type of civil society organization that are led, directed and governed by persons with disabilities, and have a mandate to speak on their behalf. Organizations of families of persons with disabilities are also considered OPDs (CRPD General Comment 7). OPDs can be umbrella or cross-disability groups as well as individual organizations representing specific disability groups. They can be national, regional and international. OPDs actually play diverse roles, including voicing the concerns of persons with disabilities, providing peer support, facilitating access to information and services (sometimes even delivering services), providing technical guidance on disability and acting as “watchdogs” on the rights of persons with disabilities. OPDs are a key component of a diverse civil society and an important contributor to democracy.¹⁴

¹² GDS Discussion Paper, Promoting engagement of organizations of persons with disabilities in development and Humanitarian Action.

¹³ GDS Discussion Paper, Promoting engagement of organizations of persons with disabilities in development and Humanitarian Action.

¹⁴ GDS Discussion Paper, Promoting engagement of organizations of persons with disabilities in development and Humanitarian Action.

A growing recognition of the added value of OPD participation

Promoting OPD participation is a way to recognize that persons with disabilities are best placed to decide for themselves. OPD participation brings multiple benefits for the relevance, quality, impact and sustainability of development and humanitarian work. It promotes ownership of interventions, accountability and better outcomes, and also supports agency and empowerment for OPDs to be long-term and efficient partners and counterparts.¹⁵

By setting an ambition to “leave no one behind,” the 2030 Agenda recognizes that development cannot be sustainable if persons with disabilities are not included. The Sustainable Development Goals (SDGs) recognize disability as a cross-cutting issue and include explicit references to disability in eleven indicators and five goals.¹⁶ The first Global Disability Summit (GDS) in 2018 was a milestone in promoting greater attention to disability inclusion. The second GDS (2022) went one step further to include meaningful OPD participation as a cross-cutting theme. [A Discussion Paper](#)¹⁷ developed to guide commitments under this theme received almost a hundred case studies as examples of OPD participation in answer to an open call. 267 commitments were made on OPD engagement, representing 25 percent of the total commitments. This illustrates the growing and unprecedented recognition for rights-based, participatory approaches to disability inclusion.

2.2 Ensuring rights-based, disability-inclusive development through inclusive programming

Meaningful participation of OPDs

As explained above, OPD participation is a core principle of a rights-based approach to disability. While there is no commonly agreed definition of meaningful participation, IDA defined it as participation that:

- respects, values and considers the **unique role and perspective of OPDs** as representative organizations ;
- enables their **regular and effective engagement** by ensuring equal opportunities for all to contribute ;
- seeks the **highest levels of shared decision-making** on all issues that concern persons with disabilities;¹⁸

¹⁵ GDS Discussion Paper, Promoting engagement of organizations of persons with disabilities in development and Humanitarian Action.

¹⁶ UNDESA, Disability and development report.

¹⁷ GDS Discussion Paper, Promoting engagement of organizations of persons with disabilities in development and Humanitarian Action.

¹⁸ IDA, Increasingly consulted, but not yet participating.

This can be illustrated with the following adaptation of the framework of participation.¹⁹ Meaningful participation is only possible when partners decide together and act together and the space is created for OPDs to lead and drive the agenda.



Figure 1: Adapted from Wilcox’s framework of participation

The first degree in engagement of OPDs is that they will be informed, including through accessible formats. However, information cannot be considered participation. Consultation, organized in ways that enable informed contribution, offers OPDs an opportunity to provide inputs and for partners to listen to their feedback, but may not give any assurance that their inputs will be incorporated.

Deciding and acting together entails an equal partnership where decisions on what is best and how to implement those interventions are taken together. The highest level of participation is leading, where OPDs drive interventions to advance their priorities and have access to enabling mechanisms including funding to do so.

¹⁹ Wilcox, The guide to effective participation.

Disability-inclusive development and humanitarian action

As with meaningful participation, there is no standard definition of disability-inclusive development. It is often understood as development that responds to the priorities of persons with disabilities, which may not necessarily include participatory approaches and a role for OPDs. In fact, OPDs report that much is being done in the name of disability-inclusive development that does not seek to consult persons with disabilities.²⁰ There is a disconnect between the intention to bring about participation and inclusion as an outcome and the processes to reach this outcome, which are not participatory and inclusive. This can also be gauged from the fact that the [2nd IDA Global Survey on OPD Participation](#) showed that even though OPDs are being consulted on a wider range of issues, preconditions for participation such as accessibility and reasonable accommodation are perceived to have deteriorated overall. Disability-inclusive development widely calls for a twin-track approach, combining disability-specific initiatives to support the empowerment of persons with disabilities with interventions that mainstream disability across all agendas. Figure 2 below illustrates the UN's twin-track approach to disability-inclusive development. However, studies show that when applying the twin-track approach, the balance tends to tip towards disability-specific services, without sufficient investment in transforming societies to be inclusive and accessible for all.²¹

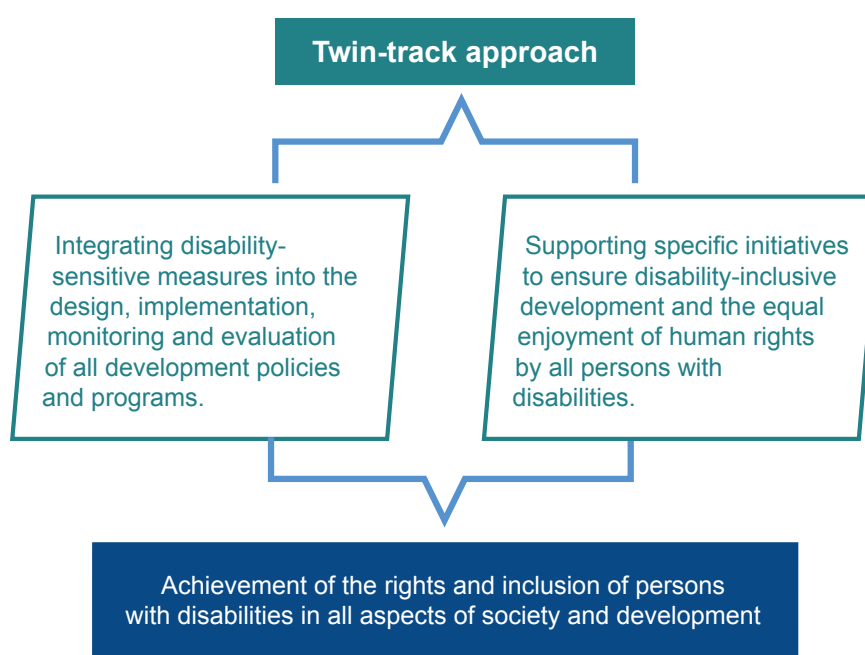


Figure 2: Twin-Track Approach to Disability-Inclusive Development (adapted from UN DPSD)²²

²⁰ IDA, “Not Just Ticking the Disability Box?”

²¹ IDA, “Not Just Ticking the Disability Box?”

²² UN DPSD, Disability and development report.

More progressive definitions of disability-inclusive development define it as development that actively seeks the full participation of people with disabilities as empowered self-advocates in all development processes and emergency responses and works to address the barriers that hinder their access and participation.²³ In situations of risk and emergency, the Inter-Agency Standing Committee (IASC) guidelines on including persons with disabilities in humanitarian action set the pathway for humanitarian actors to ensure inclusive responses that guarantee the rights of persons with disabilities will be respected, promoted and protected.²⁴

Rights-based, disability-inclusive programming

To ensure meaningful participation of OPDs into disability-inclusive development and humanitarian action, attention needs to be paid to participatory and inclusive processes. This concerns the whole cycle of designing, budgeting, implementing, monitoring and evaluating policies and programmes, as illustrated in the figure below.

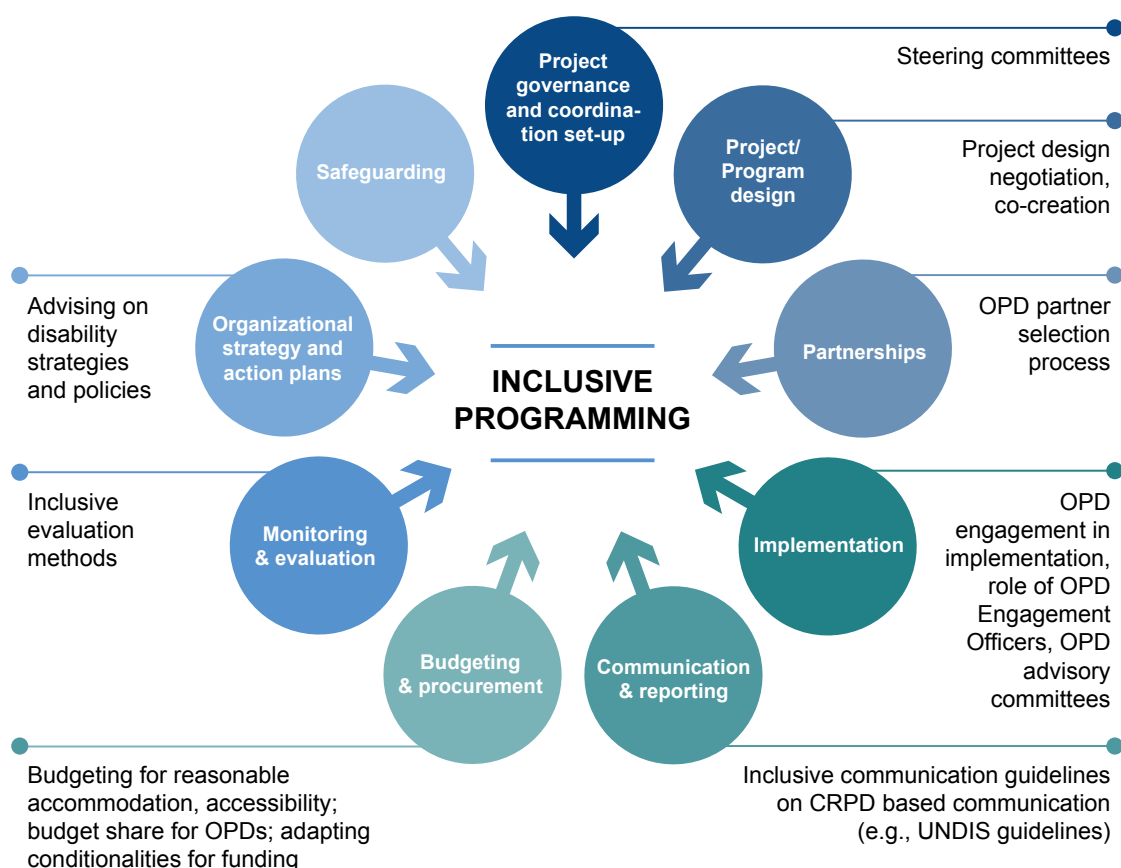


Figure 3: Processes aimed at ensuring meaningful engagement of OPDs across the programming cycle

²³ Al Ju'beh, Disability inclusive development toolkit.

²⁴ IASC, Guidelines.

Inclusive programming thus covers processes aimed at ensuring meaningful engagement of OPDs across the programming cycle, exploring roles they can play and welcoming their perspectives as a key compass to influence project orientations and ensure their relevance to the diversity of persons with disabilities. Inclusive programming requires a transformation of organizational practices to promote rights-based, disability-inclusive practices in development and humanitarian action. It requires deliberate action to set the preconditions for meaningful participation at all stages. It contributes to the shift away from OPDs and persons with disabilities as recipients of aid to promoting meaningful roles as contributors and partners.

3. Inclusive Programming: Challenges and Responses through the Inclusion Works Program

3.1 OPD participation as an afterthought

More often than not, OPDs are not part of the design and planning of development programs. The reasons for this vary and may include lack of time to co-design proposals, lack of understanding of the role of OPDs or prejudice about what they may or may not be able to contribute (e.g., project design may be considered too “complex” for persons with intellectual disabilities), lack of experience in coordinating inclusive planning sessions, or lack of motivation to move away from traditionally held practices where OPDs were looked at as recipients rather than partners, among others. Beyond tight timelines, challenges that development and humanitarian actors highlighted during the Learning and Exchange Workshop in Kenya were donor criteria for developing proposals, for example meeting certain criteria in terms of size of organization and due diligence. This often excludes OPDs that are small organizations, particularly those from underrepresented groups.

“When we have to develop proposals or funding applications, these have to be fast. On some occasions, it was difficult to engage with OPDs to get feedback on time for the application. Some donors are really flexible but some others require us to stick to the application. We need to have the information from OPDs so we can ensure that our fund applications respond to their needs from the design stage.”

— INGO representative at the Learning & Exchange Workshop²⁵

When OPDs do not participate in a program’s design, the preconditions for their full and effective participation are not fulfilled, which not only affects their participation in the project but also leads to gaps in project implementation and relevance to persons with disabilities. This was also shared by OPDs during the FGDs when speaking to their experiences in larger development programs.

“There is very little room to go and present your ideas on specific development programs. We are told that particular aspect was not included in design and therefore not considered in the budget. So, there’s nothing that can be done about it.”

— OPD participant, FGD Kenya

²⁵ Learning & Exchange Workshop on Inclusive Employment and Inclusive Programming, Kenya, May 2022.

Experience from Inclusion Works: a participatory co-creation phase can be a way to compensate for limited OPD engagement in the design of a project

While the IW consortium was formed with a role for OPDs in the governance, the engagement of OPDs across the entire project cycle was defined much later and not within the proposal. To address this gap, the IW program undertook a year-long co-creation process during which the consortium organized design workshops in each of the program countries. In these workshops, consortium partners along with national OPD representatives and other stakeholders identified the priorities on inclusive employment from their national context and defined activities towards achieving the overall program theory of change. During the co-creation, the consortium decided to establish a structure for systematic OPD coordination, which included three components (more details provided below):

- an open selection process to identify OPDs at the implementation stage rather than partners working only with OPDs that they have traditionally worked with ;
- the recruitment of OPD Engagement Officers at the national level ;
- the formation of OPD-led advisory bodies to create greater connect to the national disability movement called National Programme Advisory Committees (NPACs).

To enable these to function, a separate budget to support reasonable accommodation cost was also created.

3.2 OPD participation is still tokenistic

Despite the push for disability-inclusive development, evidence shows that OPDs are still far from being meaningfully engaged in development policies and programs. Since 2018, IDA regularly takes the pulse of OPD participation with governments and international partners through a global survey on OPD participation. The first survey revealed that while OPDs report that they are increasingly invited to contribute, participation is not meaningful. The second survey (conducted in 2021) shows that while there is overall more participation, OPDs are not satisfied with the quality of participation.

“It has to be driven by OPD participants, not led by somebody else and structured by somebody else. And if OPDs haven’t got the required experience then maybe they need some guidance – there needs to be time for that joint planning to happen. So that they have a chance to understand how they can influence things. If it’s done in a rush then it becomes tokenistic.”

— IW partner organization during a KII

Usually, the role of OPDs is mostly limited to being recipients of program interventions, or only as part of advocacy and outreach activities. Inclusive programming and meaningful engagement often require dialogue, space and time for co-production. It requires a shift in how development programs are designed and operationalized, and also how donors fund disability issues. Strict and rigid timelines and structures often mean that there is limited scope for exploring meaningful engagement to the fullest extent. Another potential risk is limiting inclusion to a value-for-money perspective rather than looking at it from the lens of equity. Often, a “business case” for inclusion is advocated, which is true in the sense that planning for inclusion in advance is more cost effective than doing it retrospectively. But inclusion requires initial investments to address the existing and historical systemic barriers. A cost-benefit approach cannot be the right lens when exclusion is so entrenched that progress will necessarily require investment.

Meaningful OPD participation and the risk of tokenism: Key findings of the 2nd IDA Global Survey on OPD Participation (2021)²⁶

1. There has been a slow and steady increase of OPD influence, with satisfaction increasing on engagement with international partners but decreasing on engagement with governments.
2. OPDs are consulted on a wider range of issues, usually matching their priorities.
3. Participation remains limited in frequency and levels of shared decision-making.
4. Many groups of persons with disabilities are still left behind in decision-making.
5. Preconditions for participation, such as accessibility adjustments and reasonable accommodation, are perceived to have deteriorated overall.
6. OPDs lack capacity, resources and opportunity to meaningfully engage.
7. The COVID-19 pandemic disproportionately impacted persons with disabilities, and also impacted the work on OPDs

26 IDA, “Not Just Ticking the Disability Box?”

Experience from Inclusion Works: a dedicated function to facilitate OPD engagement creates a mechanism to recommend and coordinate OPD engagement, and is a source of learning for both OPDs and the program

The OPD Engagement Officers in each country were recruited with the objective that they would be an on-ground support to ensure that activities within IW were meaningfully engaging persons with disabilities moving away from tokenism. The OPD EOs' role consists of spearheading coordination of OPD engagement in the project, paying attention to and supporting participation of underrepresented groups and advising program activities to reflect standards set by the CRPD. The positions were hosted within the national umbrella federation of OPDs (where it exists) and persons with disabilities with expertise on CRPD and strong connections to the national disability movement were hired in the four countries. This was very important to avoid setting a separate mechanism and disrupting or ignoring existing representation through the disability rights movements at country level.

Coordination on OPD participation in the project by OPD Engagement Officers was supported by the NPACs that fostered greater buy-in on project achievements. The role of the NPACs has been appreciated particularly for its convening abilities and to lead united advocacy efforts towards systemic changes. For example, in Bangladesh the National OPD Advisory Committee (NOAC), as the NPAC is called there, led the advocacy to demand commitments from the government of Bangladesh in the run-up to the 2nd Global Disability Summit 2022. The NOAC also coordinated the update of the chapter on Article 27 of the CRPD on the right to work for the parallel report on CRPD implementation in Bangladesh for its upcoming review in 2022.

Now that the IW program has come to a close, NPAC members and United Disabled Persons of Kenya (UDPK) have planned for the NPAC in Kenya to become a sub-committee on inclusive livelihoods under the Caucus on Disability Rights Advocacy (CDRA). The CDRA is an informal platform that brings together state and non-state actors working in the disability space. Similarly, in Bangladesh NOAC members have decided that the NOAC will become a formalized platform for OPDs to come together on common causes and will be supported through subscriptions or through volunteer contribution from the member OPDs.

However, despite this mechanism, some challenges in translating meaningful engagement into action within IW still remained. For example, some OPDs shared that their role was primarily focused on identifying jobseekers or connecting partners to persons with disabilities. The OPDs shared that they do not always have any knowledge of what happens once the jobseekers connect to the program.

“We are approached only at the time of mobilization so we are not very confident of our knowledge on the overall program.”

— OPD representative from Kenya during the FGD

The IW program had undertaken several steps to address this gap. OPD representatives were included in the Country Implementation Groups (CIGs), which was the governance mechanism at the national level. The CIGs met monthly and discussed both activities undertaken across the consortium the previous month and the planned activities for the upcoming months. This allowed for OPD partners to indicate interest in activities that they would want to engage with, in case these did not include them in the first place. OPD representatives were also included in the thematic working groups at both the global and national level, such as for advocacy, monitoring and evaluation.

Another crucial step that helped in monitoring the level of engagement with OPDs was the consortium-wide learning surveys, which were also filled out by implementing partner OPDs. The learning surveys included questions on consortium working and inclusive programming, among others.

3.3 Absence of OPDs and lack of capacity within OPDs

An issue that development and humanitarian partners flag frequently, including at the Learning & Exchange Workshop, is that sometimes in the regions and areas they work, there are no OPDs to partner with. While there is commitment within the organization to work with OPDs, at the operational level they are unable to do so.



“As advisors, we suggest the programs to have more partnerships with OPDs, but at the same time, our programs are usually in remote areas. In these areas, children with disabilities usually have more urgent needs and often we cannot find OPDs.”

— INGO partner on the larger challenge to including OPDs²⁷

INGOs and OPD representatives discuss recommendations for meaningful OPD engagement in Kenya. Copyright: IDA, 2022

²⁷ Learning & Exchange Workshop on Inclusive Employment and Inclusive Programming, Kenya, May 2022.

This also speaks to the marginalization that persons with disabilities have faced and continue to face, which has kept them from coming together as organized groups to collectively represent their issues. Leaving persons with disabilities out because there are no OPDs to work with perpetuates this cycle of exclusion. In such contexts, it is important to engage with individual persons with disabilities as an alternative while exploring ways to support movement building.²⁸

Similarly, funding conditionalities such as those mandated under donor criteria on due diligence often become a barrier, as many OPDs do not have the organizational capacity to meet these requirements. While there is larger discourse needed on ensuring the flexibility of funding modalities and proportionate due diligence requirements, steps can still be taken to address them within current development and humanitarian interventions.

Experience from Inclusion Works: proactive efforts to promote an empowering approach to partnerships with OPDs

In an effort to move away from “business as usual,” IW set an open call for expressions of interest, through which OPDs could apply to be implementing partners in the program, creating opportunities for OPDs that have not traditionally partnered with INGOs to also apply. The call was actively disseminated, including in Bengali, to underrepresented groups and included flexible conditions for funding such as fiscal sponsorship to address typical barriers that OPDs face (such as not having adequate administrative strength). Support in filling out the forms was provided to some OPDs that needed it. A selection panel that included INGO partners and representatives from the umbrella OPD, where applicable, along with IDA was constituted to identify partners from among the OPDs that applied. Involving the umbrella federation where it existed was a way to respect and reinforce OPD leadership, by initiating contacts with groups that were sometimes not represented in the cross-disability OPD. Through this process, the consortium proactively identified OPDs of women and girls with disabilities and OPDs representing persons with intellectual disabilities to engage with the project. In addition, the program also adopted a fiscal sponsorship modality, where INGO partners or larger OPDs took on the fiscal responsibilities and risks for some OPD implementing partners, helping address the lack of organizational capacity to meet due diligence criteria.

Organizational development was integrated as a component of project activities. The program applied the Three Circles Tool, through which OPDs self-reported on their existing organizational capacities, gaps and needs status, and set targets towards addressing those gaps.²⁹

²⁸ UN, Disability-inclusive communications guidelines.

²⁹ ADD International, Three circles tool.

Additionally, in Bangladesh, consortium partners included monthly and quarterly meetings of the OPDs in the program budget. This allowed for OPDs to organize meetings of their leaders, board and members more frequently not just to discuss IW activities but also for other organizational priorities. In these monthly and quarterly meetings, the OPD Engagement Officer would regularly provide sessions on CRPD and national disability laws and policies.

In Kenya, UDPK held monthly meetings with the OPDs where they shared what they had been engaged in over the past month and what they would be doing in the coming months for OPDs to find ways to work together. In these meetings UDPK would brief the partner OPDs on what was happening overall within the program. Capacity assessments were also used as a means to build the capacities of OPDs, for example organizing sessions on gender, on MEL and on advocacy. However, these meetings were affected by the COVID-19 pandemic, and later, with the budget cuts, it was decided together with UDPK to have online meetings over in-person ones and focus on other investments on OPD strengthening.

In Uganda, the OPDs under the district steering committees held quarterly meetings in their respective districts to discuss activities that have been implemented and those that are upcoming. However, this was subject to the availability of funds. In addition to this, INGO partners supported OPDs in eastern Uganda to strengthen their financial systems, resulting in some OPDs producing audit reports for the first time.

3.4 Diversity of representation

As the IDA Global Survey shows, some groups of persons with disabilities continue to be excluded from development and humanitarian programs, more so when it comes to decision-making roles.³⁰ Often the lack of organized networks representing such groups is highlighted as a barrier to including them in programs. When they are included, preconditions essential for their participation are found missing.

“It is our collective responsibility to ensure everything is accessible to all of the constituencies, we need to make sure that all of our spaces are accessible to everyone.”

— OPD representative from an underrepresented group on the larger imperative for inclusion ³¹

During the FGDs, OPD representatives shared that beyond the IW program and within the disability movement nationally, women with disabilities and other underrepresented groups are not adequately represented.

³⁰ IDA, “Not Just Ticking the Disability Box?”

³¹ Learning & Exchange Workshop on Inclusive Employment and Inclusive Programming, Kenya, May 2022.

This is for a variety of reasons, including patriarchy, cultural beliefs, lack of reasonable accommodation, lack of participatory processes, geographic remoteness and language constraints, as well as personal biases of people within the movement who assume certain groups may not be able to participate. In addition, legal barriers could exist that prevent certain groups from organizing themselves. This is especially true for underrepresented groups such as persons with intellectual disabilities, persons with psychosocial disabilities and indigenous persons.

Experience from Inclusion Works: clear and monitored criteria for diversity are needed to incentivize progress in including underrepresented groups of persons with disabilities

The IW program had a specific focus on including persons with disabilities from underrepresented groups and acknowledged the need for working with their representative organizations. While the program has acknowledged that significant gaps remained in their inclusion, several steps were taken towards this objective. In the design stage, the IW program made efforts to invite a diverse group of OPDs to the design workshops. However, participants shared that several groups were still not represented. During the start-up workshops, consortium partners actively tried to address these gaps, which led to a few more groups being included. Through the OPD selection process the program proactively identified OPDs representing women with disabilities and persons with intellectual disabilities. However, their participation in program activities continued to be a challenge, and in many cases, without ensuring the preconditions needed for the inclusion of persons with intellectual disabilities, their participation tended to be tokenistic. OPD Engagement Officers have consistently flagged the lack of diversity in program activities and recommended tracking which groups are being consistently excluded and then making proactive efforts to include them.

The OPD Engagement Officer in Bangladesh actively promoted the use of Bridge CRPD-SDGs Training Quality Criteria³² that require the participation of a certain number of representatives from underrepresented groups. Additionally in Bangladesh the OPD Engagement Officer worked with partner OPDs to follow Inclusion International's introductory resource paper "Designing Activities that Include People with Intellectual Disabilities"³³ to promote inclusive participation and facilitation in their activities, with a particular focus on underrepresented groups. This led to many OPDs including self-advocates in their activities for the first time.

In Nigeria, the OPD Engagement Officer worked with young individuals with deafblindness in the absence of a strong OPD representing the community.

³² IDA, Basic quality criteria, working principles and development of the Bridge CRPD-SDGs Training Initiative.

³³ Inclusion International, Designing Activities that Include People with Intellectual Disabilities.



Dorothy Nakato, a person with a psychosocial disability and Agnes Abukito, a person who is deafblind participate in the Learning & Exchange Workshop on Inclusive Employment and Inclusive Programming in Kenya.

Copyright: IDA, 2022

The NPACs also include members from underrepresented groups, and in Bangladesh in particular the NPAC has been very proactive in ensuring that they have a self-advocate within their executive committee.

“During the inception, we tried to find a suitable networking body of OPDs but we didn’t find any so we were working with individual OPDs but later in the third year of project an idea came from IDA and we formed a network – NOAC – National OPD Advisory Committee comprising of 18 OPDs.

— INGO Programme Staff, Bangladesh

In addition, program interventions were adapted to include reasonable accommodation and accessibility needs of a diverse group of persons with disabilities. For example, entry-level requirements for training programs were made flexible to address the fact that not many persons with disabilities from underrepresented groups have access to formal education, adaptations were made for examinations in oral formats rather than written, etc. The Accenture Skills to Succeed (S2S) learning exchange³⁴ and the Bridge IT Academy hosted by the National Industrial Training Authority in Kenya saw participation from underrepresented groups.³⁵ In Uganda, for example, the INGO partner along with the OPD Engagement Officer visited the trainees with disabilities who dropped out of the Accenture S2S pilot to understand what kind of support they need to be able to continue.

OPDs, including national representative OPDs of underrepresented groups, played a big role in the successes that IW saw in terms of inclusion of underrepresented groups. The increased awareness of the need to have self-advocates and other underrepresented groups participate in a full and

³⁴ The Accenture Skills to Succeed learning modules are a range of short online modules on employability skills such as career planning, CV and cover letter writing, interview preparation and networking. The modules that existed from before the IW programme were adapted to be more inclusive of persons with disabilities. Up to April 2022, around 1200 persons with disabilities were active on the platform.

³⁵ IDA, Equalising access to the labor market for persons with disabilities, p. 93.

effective manner also extended to partner OPDs, many of whom worked with self-advocates for the first time through this program. However, the gaps that remained in inclusion of underrepresented groups within IW highlight the larger need to be inclusive by design. Retrofitting pre-existing programs and modules is not usually effective for including underrepresented groups. It is worth mentioning that, IDA and the IW program supported the work of Inclusion International and Down Syndrome International in developing the Listen Include Respect guidelines, which is a valuable resource to understand how organizations can include persons with intellectual disabilities in their work.³⁶

3.5 Lack of data on OPD participation

Generally, a lack of reliable and disaggregated data both on the prevalence of disability and on the extent and quality of participation of persons with disabilities exacerbates the lack of participation, particularly from underrepresented groups. Even where data is available, this is often collected through national tools that are based on a medical model of disability and may significantly miss discriminations experienced by the diversity of persons with disabilities.

Experience from Inclusion Works: participation of OPDs needs to be measured throughout

Limited disaggregated data posed a challenge as the IW program evolved. It created the need for further disaggregation with increased frequency and scope for updates beyond the agreed reporting cycles and indicators. Disaggregation was integrated into program interventions, such as the Accenture Skills to Succeed Learning Exchange pilot, which collected data on the diversity within the jobseekers who registered and used the platform. Another step taken by IW was to include a section on OPD participation in the quarterly reporting template, which also nudged partners to monitor their own interventions in this regard.

When it comes to meaningful OPD participation, there is no standard data collection methodology available. Even when data is available, most focuses on the quantitative aspect rather than the qualitative side. In this regard, the IDA Global Survey provides unprecedented information on OPDs' perceptions of their role, influence and experience of participation. It has set a precedent for collecting data on who are the groups of persons with disabilities that are invited to participate, with whom they engaged, on what issues, at what level, how frequently, whether or not the preconditions needed were met and how effective was their participation.

³⁶ Inclusion International and Down Syndrome International, "Listen Include Respect – International Guidelines for Inclusive Participation".

3.6 Limited understanding of accessibility and reasonable accommodation

Accessibility and reasonable accommodation are critical enabling conditions that make meaningful participation of persons with disabilities possible. There is a general lack of understanding of what accessibility and reasonable accommodation entail, and often they are considered to be one and the same thing (see box item below). Accessibility is both a right in itself and a precondition for the enjoyment of all other rights as enshrined in the CRPD. While accessibility is subject to progressive realization, provision of reasonable accommodation is immediate and is individualized.

Even if accessibility is provided for, there will be instances when some individuals with disabilities will require reasonable accommodation. Without an understanding of the critical role accessibility and reasonable accommodation play, persons with disabilities cannot be meaningfully engaged.

Difference between accessibility and reasonable accommodation

General comment No. 6 (2018) on equality and non-discrimination ³⁷

Accessibility is a precondition and a means to achieve de facto equality for all persons with disabilities. For persons with disabilities to effectively participate in the community, States parties must address accessibility of the built environment, public transport, as well as information and communication services, which must be available and usable for all persons with disabilities on an equal basis with others. Accessibility in the context of communication services includes the provision of social and communication support.

Accessibility and reasonable accommodations are two distinct concepts of equality laws and policies:

- 1. Accessibility duties relate to groups and must be implemented gradually but unconditionally;**
- 2. Reasonable accommodation duties, on the other hand, are individualized, apply immediately to all rights and may be limited by disproportionality.**

Because the gradual realization of accessibility in the built environment, public transportation and information and communication services may take time, reasonable accommodation may be used as a means to provide access to an individual in the meantime, as it is an immediate duty.

37 UN OHCHR, “General comment No. 6 on equality and non-discrimination.”

Experience from Inclusion Works: building capacities of allies on accessibility and reasonable accommodation

The understanding of accessibility and reasonable accommodation developed progressively within the IW program. During the initial days, feedback received from participants of the design workshop reveals that most participants were not consulted prior to the workshops on the type of reasonable accommodation required. The agenda was also not designed to accommodate more frequent breaks, and documents were not shared in advance. The venues for the workshops were mostly accessible, but areas such as restrooms were not always fully accessible. Information was not available in accessible formats, including in Braille or Easy to Read. Insufficient time was allocated for some groups to prepare their contributions. It was also felt that reasonable accommodation and accessibility were often considered to be the same. Once these issues were flagged, the IW program actively took measures to address them. The program created a budget line for reasonable accommodation along with a reporting section in the financial reports. This was a critical measure which helped support the participation of persons with disabilities in program activities. Technical assistance from OPDs was made available to guide consortium partners in anticipating and implementing accessibility and reasonable accommodation measures across their activities. Positive changes within the consortium on ensuring reasonable accommodation and accessibility were increasingly visible as the program progressed, including when many activities shifted online due to the COVID-19 pandemic.

There was a demand for need for more resources to support a greater understanding of reasonable accommodation and other CRPD requirements. To address this, the OPD Engagement Officers started a column called “Insights” where they would regularly share their experience on specific issues within the program and offer guidance. They also developed a “CRPD Corner” where they would address questions on particular issues that were being raised by program partners. The pieces in the box items below are two examples where the OPD Engagement Officers address what reasonable accommodation could look like for people with psychosocial disabilities and deaf persons.

Peer support for persons with psychosocial disabilities for their meaningful inclusion: Elizabeth Ombati, OPD Engagement Officer Kenya

For many years now, in trying to find solutions for the distress I would often go through, I found community, and solace in peer support. In basic terms, it was peers – persons who, like me, had experienced mental distress in one way or another, were coming in a space of “peership.” This is a non-hierarchical space where all of us were peers, as experts by experience. Peer support for us then became a strong pillar in our lives. Within peer support as a form of social support, our psychosocial needs, our emotional needs also are a central concern, and we support each other in these dynamics too. In some of our peer support groups, we also began some income generating activities that came in handy for members in different situations of their lives.

Social support systems mean having a choice to come together, setting our own terms as peers, and deciding the best way that such support would benefit the group. These benefits include reduced levels of involuntary treatment in psychiatric institutions, reduced relapses, a feeling of belonging to community – being involved for example, documenting and addressing issues of human rights abuses at community level with the involvement of government officers.

One tool that may support the inclusion of persons with psychosocial disabilities in disability-inclusive development is to finance and support peer support models. There is also a need to continue to put focus on the group and to find further ways to support their meaningful inclusion.

Reasonable accommodation for deaf persons: Betty Najjemba, OPD Engagement Officer, Uganda

Sharing her own experience as a deaf woman, the OPD Engagement Officer from Uganda reflects on the barriers she faced within her community and offers some insights on what society should do to support the meaningful inclusion of deaf people. As she notes, while the provision of a sign language interpreter is a good starting point, that does not by itself translate into effective and full participation.

In fact, there's much more to it, as outlined below:

- All sign languages are not the same. Most sign languages tend to differ across continents and even within the country. The key therefore is to provide a sign language interpreter that the user follows and not to assume that a locally provided sign language interpreter will always work.
- Do not assume that the sign language interpreter from one region can also speak the language of the local community. So, if and when the nature of the work demands that the deaf person interact with the local community, he/she should be provided an interpreter who understands the local languages and can voice the local deaf people's interventions.
- The quality of interpretation depends on the training and exposure of the sign language interpreter. In the case of technical and complex activities, especially explaining the CRPD or human rights issues, make sure the sign language interpreter has familiarity with such work.
- Sensory breaks are essential for the interpreter and the deaf person, as otherwise it leads to fatigue. For meetings of an hour or more, ensure two sign language interpreters are present so that they can switch every 20–30 minutes.
- Advance preparation and sharing of documents and important information ahead of the event/activity is critical for the sign language interpreter and the deaf person.
- Speaking audibly, clearly and at a regular pace is essential for the interpreter to be able to deliver. Without this some words may go unnoticed and the deaf person may either miss the whole context or misunderstand what is being said.
- Too much content and technical jargons that require complex signs or spelling out words may deter a deaf person from understanding parts of the discussions, especially if they are new to the concepts being discussed. Try to keep the content simple!
- It's important to check in with the deaf participants from time to time about whether the delivery of the presentation is okay or if anything requires further clarification.
- Factors like seating arrangements, lighting quality, and not speaking over one another are also important concerns that need to be kept in mind.

3.7 Budgeting for meaningful engagement of OPDs

Like any other social movement, OPDs also exist on a spectrum in terms of organizational capacities. Often OPDs, particularly those that represent underrepresented groups, are not even registered. On one hand, this means that OPDs are seldom able to meet the funding conditionalities imposed by donors to access funds independently, with most donors preferring to work with INGOs as intermediaries. On the other, as OPDs get increasingly solicited to participate in programs that do not support the opportunity costs of participation, it often compels them to either prioritize issues that are critical but not financially supported over funded issues, or not participate at all.

Done well, DPO³⁸ engagement can provide mutual benefit, with development programs improving their reach and effectiveness, and DPOs expanding their voice, gaining influence and receiving resources. Done poorly, DPO engagement risks diverting DPOs from their own priorities, overwhelming their capacity and available resources, and perpetuating the marginalisation already experienced by many people with disabilities.³⁹

Experience from Inclusion Works: budget allocations need to reflect participation as a key objective

Initially in the proposal, IW did not include a clear OPD engagement plan or budget for an OPD coordination mechanism. The proposal development phase was more focused on establishing consortium relationship and roles. However, it was soon evident during co-creation that the consortium needed both a plan for OPD engagement and budgets to implement it. The OPD coordination mechanism and a separate budget line on reasonable accommodation were therefore included. The positions of the OPD Engagement Officers were also included during co-creation. Due to the different structure of engaging with OPDs, not all OPD partners had budgets available to support OPD organizational strengthening, including staff costs. During the FGDs, OPD partners consistently raised the lack of budgets for salaries and compensation for loss of income as a significant barrier to participation. This particularly affected the participation of underrepresented groups. When considered within the context of COVID-19 induced budget cuts, it meant OPDs had to realign program priorities with limited financial resources.

³⁸ DPO stands for disabled people's organization, a term which has now changed to OPD (organization of persons with disabilities) in keeping with the person first language advocated by the CRPD.

³⁹ Wilson, "Creating a new 'business as usual.'"

This not only affected implementing partners but also had a bearing on the participation of OPDs, many of whom faced huge opportunity costs as their capacities and resources were stretched to the maximum.

“I have a poultry farm where I work full time. When I have to participate in IW meetings or activities, I cannot work. This causes financial loss to me and since this is a project, this is not an occasional loss – it happens on a regular basis. Project personnel of INGOs get salaries, why should we invest our time and resources voluntarily?”

— President of an OPD in Bangladesh

This was addressed to some extent by providing stipends for participating in program activities and by supporting organizational strengthening of OPDs. The work of the OPD EOs was also not included in the initial budget. Consortium partners in some countries found a way around by including travel and reasonable accommodation costs for OPD EOs in their field activities. In Bangladesh, ADD and Sightsavers Country Offices also supported NPAC meetings, including inviting them to capacity-building workshops where IDA provided support in defining the methodology and facilitating. However, this again shows that meaningful engagement of OPDs needs systems that are in built within the proposal. The IW program addressed the impact of budget cuts by prioritizing activities that supported capacity strengthening of OPDs over other issues such as community awareness raising and behavioral change communication.

3.8 Training of all staff on inclusive programming

As defined earlier, inclusive programming focuses on the processes and how to ensure meaningful engagement of OPDs across all these processes within the project cycle. It requires organizations to have policies and systems in place that identify and address barriers that impede meaningful participation. Therefore, it is important that the core principles of inclusion and participation are engrained from the leadership to the operational staff within the organization. It is often noticed that while the leadership, especially at the global level, are more aware and accepting of inclusive programming, it does not automatically trickle down to the staff at the ground level implementing projects.

“At the operational level, budgeting for disability inclusion or OPD participation is not clearly understood. When budgets have to be reduced, the funding for reasonable accommodation is usually the first to be cut.”

— INGO representative during the Learning & Exchange Workshop on larger challenges in meaningful engagement of OPDs⁴⁰

40 Learning & Exchange Workshop on Inclusive Employment and Inclusive Programming, Kenya, May 2022.

Experience from Inclusion Works: CRPD-based inclusive programming and meaningful OPD engagement can be fostered by OPD-led training as a multi-pronged process rather than a one-off event

At the beginning of the IW program, the consortium developed a document on “Principles & Values” that emphasized inclusion and accessibility as at the core of the program (see box item below). Although this document was available to access, awareness of it among program staff at national level was limited for a number of reasons, including staff turnover. During the course of the program, IDA supported two workshops on CRPD for consortium partners, in 2019 and 2020. While the 2019 workshop was more on normative components of inclusion, the 2020 one was more to address the “how to” of meaningful engagement of persons with disabilities. Some partners started committing to meaningful engagement of OPDs, including those that till now have not worked on disability issues. In August 2020, the consortium conducted a survey among partners to understand the level of awareness and knowledge on CRPD and OPD participation. Many respondents asked for more practical resources on how to engage with OPDs to co-develop activities and understanding how to budget for participation. This further points to the need for practical tools and training for program staff on CRPD and inclusive programming.

Inclusion Works: Principles & Values

The Inclusion Works consortium committed to upholding its core Principles and Values which promote inclusive ways of working, both internally and externally across all programme activities, and which seek the participation of all members and both encourage and respect diversity. Some of these principles include:

- Diversity and representation
- Inclusivity and participation of persons with disabilities
- Non-discrimination
- Accessibility and reasonable accommodation
- Accountability, including to persons with disabilities

In 2019, Inclusive Futures developed its handbook on monitoring, evaluation and learning (MEL). The handbook included an annex on the need to track inclusive programming and OPD participation along with a short session during the MEL staff training.

The need for training of staff also extends to outward-looking functions such as communication. It is not only important to have a CRPD-based approach to program implementation; it is equally important to talk about persons with disabilities in a way that reinforces disability as part of human diversity, rather than as objects of pity or as heroes for “overcoming” their disability. In Inclusion Works, the IDA Inclusive Livelihoods Task Team developed a discussion paper on CRPD-based communication to guide the program. This was used by the Communications Working Group, comprising representatives from different consortium partners, to further build on to create guidance to make consortium-wide communication rights based.

It needs to be mentioned that training on inclusive programming should not be a one-off event. In fact, this should be part of an organization’s regular policies on staff on-boarding and training across all functions, and safeguarding. It is also important that these policies are developed in close collaboration with OPDs.

The experience of the OPD Engagement Officers also speaks to the need for staff training on a consistent basis.

“I get calls from partners informally asking questions around if a certain group is considered in the definition of disability or not. While this may seem like a very basic question, it shows how having a technical resource or having access to technical expertise can support development actors to start asking the simple questions that are key to inclusion.”

— OPD Engagement Officer, Kenya.

Another important issue that is linked with transforming organizational culture on inclusion is to recruit more staff with disabilities, who can also bring their unique perspectives to drive inclusive programming. However, it is important that the mandate to represent the disability movement remains with OPDs.

CRPD-based communication on disability

Communication cuts across all our work and sets the narrative around how our work is perceived and understood. A narrative that is not built on human rights and equality will reinforce negative attitudes, which often lead to discrimination and harmful practices. Therefore, it was imperative that communication around IW was built on the CRPD principles.

To support the communication team in sharing stories and testimonies from the program in a rights-based manner, IDA developed a discussion paper on key elements of CRPD-based communication. This covered the issue of ableism and how it reinforces negative stereotypes (such as living with disability as something either heroic or pitiable), accessibility of communication material and respecting the autonomy of persons with disabilities to tell their stories from their own lens. Some of the guidance provided includes, but is not limited to:

- Using terms that are accepted by the movement of persons with disabilities over euphemistic or patronizing language, be it in English or other locally spoken or national languages. For example, avoiding terms like “differently abled,” “special abled,” “handicapped,” “mentally challenged,” “mentally ill,” etc.
- Using person-first language, which means that in all communications individuals and groups should be referred to as “(a) person(s) with a disability,” not “(a) disabled person(s).”
- Using a social model over a medical and charity model, which could include avoiding glorifying overcoming of disability, avoiding terms like “in spite of” and “despite,” and showcasing prevention or remediation of impairment over creating inclusive environments and systems, among others.
- Avoiding terms such as “beneficiaries,” “recipients,” “vulnerable,” “victims” and “suffering from” that reinforce the idea of people with disabilities as objects of charity. Instead, terms such as “stakeholder/participant” should be used to reflect the relationship of people with disabilities to projects, and “marginalized or underrepresented” should be used to reflect individuals’ backgrounds or experiences.
- Ensuring accessibility of all communication products and systems to persons with disabilities.

41 UN General Assembly, Human Rights Council, “Awareness-raising under article 8 of the Convention on the Rights of Persons with Disabilities,” para. 4.

Key takeaways

- From the very beginning, programs must adhere to the principles of the CRPD and of meaningful engagement of OPDs demonstrated through OPD engagement plans with adequate budgets, a commitment to engage with a wide range of OPDs through open OPD identification processes and ensuring accessibility and reasonable accommodation throughout the program.
- Development actors, including donors, must put in place processes that allow for co-leading rather than co-optation of OPDs. In addition, donors need to provide budgets that enable the creation of support services that are essential for inclusive programming and meaningful engagement of OPDs.
- Inclusive programming and meaningful OPD engagement cannot happen without the existence of a strong disability movement represented by OPDs from a diversity of disability groups. Proactive efforts are needed to ensure that OPDs are supported to strengthen their organizational and technical capacities that enable them to respond to the growing demands from them to engage in development processes and programs.
- Meaningful OPD engagement is a collective commitment that each organization has the individual responsibility to implement. It cannot be done by OPDs for them even though OPDs can provide crucial technical support.
- Inclusive programming requires transforming organizational culture on inclusion, including policies, regular trainings, resources and hiring staff with disabilities.
- There is a critical need for more practical guidance and resources to support the operationalization of inclusive programming.

4. Recommendations and Conclusion

4.1 Recommendation for inclusive programming across the project cycle

While there is a growing discourse on meaningful engagement of persons with disabilities, translating it to action has been a challenge. There is still very little discussion on how inclusive programming looks like in practice. A common ask from program and operational staff within the IW program was for clear guidance and tools to help implement inclusive programming. This section will look at some of the steps that IW took at different stages of the project cycle and provide recommendations informed by the discussions with OPDs, INGO partners, UN bodies and donors, including feedback from the Learning & Exchange Workshop on Inclusive Employment and Inclusive Programming in Kenya in May 2022. This is not an exhaustive list but a starting point for more discourse on inclusive programming towards achieving the goal of highest level of participation, where OPDs drive interventions to advance their priorities and have access to enabling mechanisms including funding to do so.

Project design

IW added a period of co-creation with OPDs where they were invited to national design workshops. The program adopted an “adaptive management” approach that was flexible to innovative changes to the program design. However, one of the challenges during this co-creation was the feedback loop to the OPDs for them to know how their inputs were incorporated. This speaks to a need to reiterate that inclusive programming is a two-way process and cannot be looked at as a one-off event.

Steps that can be taken at this stage:

- **Include OPD representatives** in the development of project proposals, clearly articulating their roles across all stages of the project, including resources to be made available for them.
- **Include a co-creation process** to develop the project together with a diversity of groups of OPDs, including from underrepresented groups. Plan sufficient time and create preconditions for meaningful engagement.
- **Communicate clearly** about the project at the grassroots for more OPDs to have the chance to engage.



Inclusion Works partners and OPDs participate in a group activity during the IW launch workshop in Bangladesh.
Copyright: Sightsavers, 2019

Project governance

In IW, OPDs were included in the Country Implementation Groups (CIGs), which were the national-level governance structure of the program. CIGs met monthly and partners shared updates on activities of the past month as well as on upcoming activities. This helped OPD partners to be aware of program activities and also indicate in advance if they would like to engage with any of them, and encouraged proactive collaboration between all members. In addition, OPDs were included in working groups that led thematic areas such as on advocacy or MEL. In Bangladesh, the program supported monthly meetings of the OPD partners at the district level that became another level of monitoring of the implementation of activities. A monthly meeting guideline was developed by partner OPDs with the support of the OPD EO that set targets for the OPDs to achieve, and every month progress was tracked against these. The guidelines also advocated for sharing of upcoming activities so that OPDs that would want to engage have prior information on them.

Steps that can be taken at this stage:

- **Clearly define the role of OPD representatives** within the decision-making processes of the project, with a feedback mechanism to reflect how their inputs are being taken into account.
- **Define a mechanism for OPD engagement** that cuts across the program components and lifespan.
- **Ensure that the mechanism for OPD engagement is well coordinated** with the umbrella OPD federation and contributes to strengthen rather than challenge leadership of the disability rights movements at the country level.
- **Establish a bottom-up approach to governance** with clear communication pathways, instead of a top-down approach.

Partnerships

The OPD selection process of IW was an innovative way to create an open and accessible process for OPDs to partner with the program. More importantly, it allowed an opportunity to OPDs that have not traditionally worked with these INGOs or been involved in development programs of this magnitude to do so. The program also adopted fiscal sponsorship, where INGO partners took on the financial management for OPD-led activities in case the OPD did not meet the due diligence criteria of the donor. Sometimes the umbrella OPD or a larger OPD became a fiscal sponsor based on mutually agreed terms.

IW also fostered stronger partnerships between different program partners. For example, the Business and Disability Networks in Kenya and Nigeria have close partnerships with the national disability movements with OPD representatives on the board. Similarly, several INGO partners who had so far not worked on disability also started to engage with them, some of them committed to continuing their work on disability inclusion beyond the life of the project.

Steps that can be taken at this stage:

- Partnerships with OPDs, including underrepresented groups, should not be an afterthought. **Establish open, accessible processes** to enable OPDs, including those representing underrepresented groups, to express interest to engage as partners.
- **Define the level of partnerships** (e.g., implementing partners, technical partners, knowledge partners, advocacy partners) so that OPDs can indicate interest based on the level of engagement they decide for themselves within the project.
- **Adopt flexible processes** to keep funding conditionality from becoming a barrier to partnerships.
- **Categorize project activities** into smaller parts so that OPDs can choose where they fit best as per their capacity. Smaller OPDs or those from underrepresented groups may prefer to be part of smaller activities and hence may not engage if the only room for them is to take on huge project responsibilities beyond their capacity.
- **Establish partnerships that respect the OPD structures and leadership**, rather than creating competition.

Budgeting

As elaborated earlier, inclusive programming requires budgets that are incorporated during the design and development of the project. Without adequate resources to support meaningful OPD engagement, inclusive programming will not be realized. While IW did not initially have an OPD engagement plan with associated budgets, it agreed on an OPD coordination mechanism during co-creation. It allocated funds to support reasonable accommodation costs for OPD participation. In addition, it also reallocated funds from existing budget lines to support the recruitment of OPD Engagement Officers. The program leveraged project activities to create opportunities for OPDs to have their own organizational meetings that in turn supported the strengthening of OPD capacity. Some OPDs also raised the point that they only had funding for earmarked activities and not to support their staff time or other organizational costs. This was addressed by providing stipends and also investing in organizational capacity strengthening of OPDs, including through the Three Circles Tool, safeguarding workshops and technical support on putting in place administrative processes.

There were also no earmarked budgets to support the functioning of the OPD Engagement Officers and the NPACs, which impacted their work at times. This was addressed to a certain extent in Bangladesh and Uganda, where the implementing INGOs included travel and reasonable accommodation costs for OPD EOs in their field activities. In Bangladesh, ADD and Sightsavers Country Offices also supported NPAC meetings, including inviting them to capacity-building workshops where IDA supported with defining the methodology and facilitating.

Steps that can be taken at this stage:

- **Allocate adequate resources** for meaningful engagement of OPDs, in consultation with them, including supporting staff time and enhancing operational capacities of OPDs.
- **Include budgets for the cost of inclusive procurement** to support accessibility of activities (e.g., Braille, sign language interpretation, captioning, illustrators, language interpreters), products, information, etc.
- **Support OPDs** to develop capacities on budgeting and compliance requirements.
- **Develop accessible tender processes** and include OPDs as vendors or service providers.

Project activities

Within the Inclusion Works program, OPD engagement was a cross-cutting theme in the program, and capacity-building of OPDs was a core output area within the results framework, activities and program structure (including the Theory of Change). Activities were implemented in partnership with OPDs or in close collaboration with them. A question that operational and program staff often raised was whether each and every activity needed an OPD partner. The program clarified that OPDs as implementing partners without decision-making roles is also a form of tokenism. The objective is to co-develop activities with the active participation of OPDs – activities that are aligned to the priorities of the disability movement – and not to assume in advance the types of roles that OPDs can or cannot take.

Steps that can be taken at this stage:

- **Have clearly defined roles for OPDs** in project activities.
- **Have meaningful roles for OPDs** in technical areas and not only for outreach and advocacy or to mobilize their membership.
- **Strengthen project activities** by aligning them with OPD priorities on those issues.
- **Develop, along with OPD partners, clear guidelines for meetings and events** that foster inclusion of a diversity of disability groups.
- **Establish feedback mechanisms** to continuously enhance inclusion in project activities.
- **Have clear guidelines for organizing workshops**, meetings, trainings and other interventions that include quality criteria on levels of accessibility, inclusive facilitation checklists, diversity of participation, etc.

Monitoring and evaluation

In the IW program, the role of OPDs in monitoring and evaluation varied from country to country. OPDs were represented in the MEL working groups set up at different levels within the program. At the global level, OPD partners were part of the development of MEL tools. As mentioned earlier, limited disaggregation of data posed a challenge that called for further disaggregation with increased frequency and scope for updates. Data disaggregation was integrated into all program activities.

In terms of reporting on program activities, the quarterly narrative report included a section on OPD engagement. In addition, financial reporting templates included a section on expenditure on reasonable accommodation.

Steps that can be taken at this stage:

- **Include disability-related indicators** and disaggregate data by disability, gender, age and other relevant parameters.
- **Use globally accepted tools** that provide reliable and comparable data.
- **Include collection of data** on the extent and quality of OPD engagement (e.g., [IDA Global Survey on OPD participation](#)⁴²) in MEL practices.
- **Include CRPD-based MEL practices** in training modules and train staff working on monitoring and evaluation.
- **Consult OPDs on any accessibility considerations** for reporting or options for alternative formats that could be provided.
- **Work with OPDs to collect disability data** and also strengthen capacity of OPDs on data collection practices.

Communication

One of the challenges of communication on disability issues is the tendency to focus on overcoming of challenges and individual triumph rather than looking at the systemic barriers that keep persons with disabilities out of the mainstream. This perspective stems from internalized ableism.⁴³

Inclusive Futures communication also dealt with such challenges initially. However, the Inclusive Futures communications partners worked together to understand the necessity to use empowering language, how the CRPD is relevant to communications, and phrases that are aligned with the CRPD.

⁴² IDA, “Not Just Ticking the Disability Box?”

⁴³ Ableism is a value system that considers certain typical characteristics of body and mind as essential for living a life of value. Based on strict standards of appearance, functioning and behaviour, ableist ways of thinking consider the disability experience as a misfortune that leads to suffering and disadvantage and invariably devalues human life. As a result, it is generally assumed that the quality of life of persons with disabilities is very low, that they have no future to look forward to and that they will never live happy and fulfilling lives. (UN General Assembly, Human Rights Council, “Rights of persons with disabilities,” p. 3, para. 9).

The consortium explored how to communicate practices on the ground that are not CRPD compliant, and how to provide a caveat or a rights-based explanation on why the practice is not advocated anymore. IDA developed a discussion paper on CRPD-based communication that supported these conversations. The Inclusive Futures communications partners developed a background presentation based on the discussion paper on CRPD-based communication, including some do's and don'ts. The Inclusive Futures communication team actively promoted the use of empowering language in their engagement with external partners. Of late, CRPD-based communication has gained ground with the development of guidelines under the UN Disability Inclusion Strategy.⁴⁴

Another challenge in communication is the use of jargon and technical language that is difficult to communicate across all groups of persons with disabilities. This also includes internal communication. One way in which the IW addressed this was by publishing its internal newsletter in plain language to make it more accessible.

Steps that can be taken at this stage:

- **Follow a rights-based approach** in reporting on project activities or on disability in general.
- **Develop clear guidelines**, in close collaboration with OPDs, for communicating on project activities, including on social media (see UNDIS guidelines on communication⁴⁵).
- **Include minimum accessibility standards for the project** (e.g., an accessibility checklist) in communication guidelines, including for internal communication.
- **Adopt best practices developed by OPDs**, and include OPDs in the development of communication plans.

Safeguarding and organizational policies

The IW program recognized the importance of inclusive programming being rooted in organizational policies, including on safeguarding. Although it is difficult to show concrete examples of organizational policy changes that happened during the four years of the program, activities within the project targeted systemic and organizational changes with external partners such as employers. Within the consortium, inclusive safeguarding policies were critical discussions. At the global level, Inclusive Futures, through its members, collaborated with the Resource and Support Hub (RSH) on disability-inclusive safeguarding policies. At the national level, INGO partners organized safeguarding trainings for OPDs. However, the issue of disability-inclusive safeguarding policies needs much more critical attention beyond the IW program. They have to be underpinned by the CRPD, and the language associated must be empowering rather than reinforcing stereotypes that some groups may need “special protection.”

⁴⁴ UN, Disability-inclusive communications guidelines.

⁴⁵ UN, Disability-inclusive communications guidelines.

Steps that can be taken at this stage:

- **Establish policies**, including safeguarding policies, and action plans that are disability inclusive. This is applicable not just to project related policies but also to larger operational policies of organizations.
- **Conduct regular trainings on disability-inclusive safeguarding**, especially keeping in mind lived experiences of persons with disabilities themselves (e.g., include trainers with disabilities).
- **Make sure to get the buy-in of top leadership for organizational policies**, including on recruitment.
- **Make all organizational policies**, including on safeguarding, available in accessible formats.
- **Ensure multiple channels for feedback and reporting**. Make sure a safe space that is accessible for all is created.
- **Support OPDs**, particularly those that are program partners, to develop safeguarding plans and allot a reasonable time.

4.2 Conclusion

Inclusive programming is critical to achieving the realization of the CRPD and the successful implementation of the SDGs. Despite the mandate of the CRPD and the principle of “Nothing about us without us,” systemic barriers have kept OPDs from effectively leading disability-inclusive programming and driving the agenda. There is a vicious cycle where the lack of capacity to engage in programming is often a barrier to inclusion, and this exclusion from development and humanitarian programs in turn perpetuates the lack of capacity.

Breaking this cycle requires transformative changes. It also requires a shift in the current power asymmetry. Investing in OPD strengthening and ensuring meaningful participation of OPDs is a critical driver to achieve this transformative change. As the discourse on disability inclusion moves away from *whether* to include to *how* to include, there will be an increasing demand for accountability and moving away from tokenism. We are already seeing that shift in attention to OPD engagement, as is evident through the Global Disability Summit mechanism and increasing donor interest in realizing full and effective participation of persons with disabilities.

The IW program provided learning on inclusive programming and, more importantly, an experience of collaboration that was not always smooth but was part of the success. Transforming practices and organizational and partnership cultures takes time and requires direct experimenting. However, we hope that recommendations from this report can be useful to inform further experiences aiming at investments that lead to higher levels of OPD participation to leave no person with disability behind.

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6. Annexes

6.1 Primary data collection

Bangladesh

Organization	Interviewees/Participants of FGDs
Inclusion Works partner OPDs	OPDs representatives
Action on Disability and Development	Project Manager
Bangladesh Business and Disability Network	Head of Operations
Sightsavers	Programme Officer

Kenya

Organization	Interviewees/Participants of FGDs
Inclusion Works partner OPDs	OPDs representatives
Sightsavers	Programme Manager
Sustainable Hospitality Alliance	Partnerships Manager – Africa

Uganda

Organization	Interviewees/Participants of FGDs
Inclusion Works partner OPDs	OPDs representatives
Development Initiatives	Senior Analyst; Partnerships and Engagement Manager
Sightsavers	Programme Manager

Nigeria

Organization	Participants of FGDs
Inclusion Works partner OPDs OPDs	OPDs representatives

Global

Organization	Interviewees
Inclusion International	Project Manager
Institute of Development Studies	Research Fellow
Development Initiatives	Lead Analyst
Sightsavers	Programme Manager

