

The unsteady path

Towards meaningful participation of Organisations of Persons with Disabilities in the implementation of the CRPD and SDGs.
A pilot study by Bridging the Gap

Research coordinated by
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Bridging  the **GAP**

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Editor

Bridging the Gap project: Inclusive Policies and Services for Equal Rights of Persons with Disabilities

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“The disability sector is the only one – neither women nor indigenous people – for which the law compels the ministers, the vice ministers to sit at the table and we haven’t yet taken advantage of this situation to have an impact and to transform”

Public official in Paraguay

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Introduction

Modelled on the unique level of civil society participation in its negotiation, the Convention on the Rights of Persons with Disabilities (CRPD) clearly stipulates the obligations of States Parties to consult and involve persons with disabilities through their representative organizations (OPDs), in the implementation and monitoring of the CRPD (article 4(3) and 33(3)). This emphasis on participation of persons with disabilities has been a response to their systematic exclusion from consultation and decision-making mechanisms related to design, planning and monitoring of policies, programs and services that affect their lives and their communities.

In its dedicated 2018 General Comment Seven (GC7), the CRPD committee notes the progress made by States Parties to implement some of the more formal obligations under articles 4 (3) and 33 (3) (such as including persons with disabilities in independent monitoring frameworks, consulting with OPDs in the preparation of their CRPD initial and periodic reports), but also insists on the absence of meaningful consultation with OPDs in the development and implementation of policies and programs. Recalling the diverse barriers that undermine their participation, the general comment highlights and clarifies the obligation of States Parties to create an enabling environment for OPDs participation.

International cooperation, particularly in Low- and Middle-Income Countries (LMICs) is pivotal for the strengthening of civil society capacity to hold government accountable and to engage in policy advocacy. In light of their own obligations under CRPD, in particular article 32 on international cooperation, development agencies have a particular role to play in supporting representative organizations of persons with disabilities both in terms of capacity building and effective participation (UNSRPD, 2018).

The ratification, implementation and monitoring of the CRPD and the no one left behind focus of the Sustainable Development Goals have created unprecedented opportunities for engagement between organizations of persons with disabilities (OPDs) and governments or development agencies. In many countries, there have been disability related legislative and policy reforms, development of specific policies and an increasing attempt to include persons with disabilities in development and humanitarian programs. This has indeed generated an increase of involvement of OPDs as evidenced by International Disability Alliance recent global survey on OPDs engagement.

However, there has been little review to date of the effectiveness and quality of this engagement in LMICs as shown in recent dedicated literature reviews (Price, 2018 and Young, 2016). There are also concerns that due to their limited institutional capacities, OPDs may face severe opportunity costs in choosing to engage with multiple development agencies at the expenses of sustained and deeper engagement with central and local authorities, which may not been seen as responsive and not in position to provide very needed resources.

The present study, commissioned by the Bridge the Gap project, seeks to provide an overview of the situation in project's partner countries (Burkina Faso, Ecuador, Ethiopia, Paraguay and Sudan) and to formulate recommendations to international cooperation actors on their possible contribution to strengthen meaningful participation of persons with disabilities in the implementation of the CRPD and the Sustainable Development Goals (SDGs). It complements other efforts currently carried out, such as the International Disability Alliance (IDA) global survey of OPDs engagement with governments and development agencies.

Considering the vast range of issues covered by articles 4.3 and 33.3 and the resource and time constraints, the study focused mostly on the interaction between governments and OPDs as intermediary bodies representing the diversity of persons with disabilities with the aims of ensuring their meaningful participation at national level.

The study combined a review of the literature and interviews with representatives of governments, OPDs, service providers, mainstream civil society organisations and development agencies across the 5 countries carried out between August and November 2019 to provide a multi stakeholders perspective on the participation of OPDs in CRPD. It also developed an analytical tool to collectively understand different forms of interaction and participation that could be further developed and used for further studies.

The report is structured in 3 parts:

- **Part 1** presents the scope of the study, the methodology and conceptual framework
- **Part 2** synthesises country case studies from the Bridging the gap countries
- **Part 3** proposes recommendations to international actors to support meaningful participation of persons with disabilities in implementation of the CRPD

Part 1: Scope and Methodology

1.1 Scope of the study

As mentioned, the study focused on the measures in place to ensure meaningful participation of persons with disabilities through their representative organisations at national level and the type and influence of the relation between authorities and OPDs as compared with the standards established by the CRPD committee in GC7.

The study did not attempt to analyse in depth the disability movement dynamics and evolution, the conditions for engagement of persons with disabilities themselves nor the actual representativeness of OPDs. Similarly, it did not attempt to understand intra-governmental dynamics and issues between ministries and level of authorities which certainly impact the extent and quality of their engagement and ultimately participation of persons with disabilities. Also, participation in the context of decentralisation, which is important in several Bridging the Gap (BtG) countries, could not be looked equally and therefore is not considered as a specific issue. All those elements are essential to understand overall participation of persons with disabilities and worthwhile investigating further but would require significantly more time and resources.

Also, it is important to note that the study is based on the perception of the different stakeholders and is not an objective evaluation which would have required different methodology and resources.

The study considered that meaningful participation may have, among others, two simultaneous but not necessarily synonymous aims:

- As a human right of persons with disabilities to be consulted and to influence policies and public decisions that impact their lives (an end in itself).
- As a mean to ensure that governments develop the best policies and programs possible and optimum allocation and use of available resources for the realisation of all human rights of all persons with disabilities in a given context (a means to an end).

However, acknowledging the political nature of public participation, the study acknowledges that participation can also be used to legitimize policies and processes that preserve status quo or perpetuate inequalities.

The study also considered that achieving meaningful participation, while a human right obligation of states, is a co-production - a two (and a half) way process as in any given context. States and OPDs will adopt strategies and tactics in relation to one another with sometimes significant impact from other actors such as service providers and/or donors and international development agencies. The study also takes into consideration that most of the countries of the studies are challenging political contexts.

Based on the conceptual framework, the study seeks to assess:

- ▶ The understanding, challenges and opportunities for “meaningful participation” from an OPDs’, as well as government and donors’ perspectives in the project’s partner countries (Burkina Faso, Ecuador, Ethiopia, Paraguay and Sudan).
- ▶ The extent to which governments create an enabling environment for meaningful participation of OPDs and the current practices in terms of participation:
 - » Creation of a legally, administratively and politically enabling environment for meaningful participation including by providing support to establishment and functioning of OPDs
 - » Seeking true engagement with OPDs at least to co-design, implement and evaluate policies and programs and possibly co-manage
 - » Reaching out to all groups in an inclusive manner
- ▶ The different types of relation existing between Government and OPDs in their path towards achieving meaningful participation of persons with disabilities.
- ▶ Donors and international development agencies contribution in enabling meaningful representation OPDs:
 - » Do not inadvertently negatively impact meaningful participation
 - » Support capacities of both OPDs and authorities to engage
 - » Foster dialogue between OPDs and authorities as well as demonstrate by exemplarity the benefits of and ways to achieve meaningful participation

The study did not consider specific sectors but look at the overall trends and elements related to participation due to the heterogeneity of policies and programs in the different countries and the resources available for the study.

1.2 Methodology

The CRPD standards, elaborated upon in GC7, have to be implemented in national contexts which vary widely in terms of civil society development, political situation, rule of law, governance, freedom of speech and associations among other elements. While there has been research efforts to understand active citizenship and political engagement of OPDs in high income countries in relation to the CRPD (Waldschmidt, 2015), the study could not identify significant related literature with regards to LMICs, especially on the interaction between authorities and OPDs as representatives of persons with disabilities, and on the role of international cooperation.

Also, while the GC 7 logically focuses on many disability specific issues, meaningful participation of persons with disabilities, through their representative organisations, to public policy decisions that impact them is also inherently related to more general issues of public participation and engagement with civil society. This is very significant if we consider countries with restricted civic space, which is the case of most of BtG countries.

The study therefore chose to work mostly on the mainstream literature primarily related to public participation and its politics, the relationship between state and civil society organisations as intermediary bodies, as well as elements related to the shrinking of the civil space and the role of international actors. This literature provided broader elements to develop a framework for the analysis of the CRPD standards implementation.

The CRPD normative framework

The principle of right to participation in public life is well established in international human rights instruments including in the Universal Declaration of Human Rights (art. 21), International Covenant on Civil and Political Rights (art. 25), International Convention on the Elimination of All Forms of Racial Discrimination (art 5 (c)), of the Convention on the Elimination of All Forms of Discrimination against Women (art. 7), and) of the Convention on the Rights of the Child (art. 12 and art. 23 (1)) and the Convention on the Rights of Persons with Disabilities (art. 4(3) and art. 33 (3)). In recent years, UN institutions set minimal level of obligations and expectation in relation to meaningful participation under International human rights law which could be summarised as follow:

- Respect of equal recognition before the law, freedom of association, freedom of expression and opinion, right to political participation and taking part in public life to create a safe and free space and process for participation.
- Involving people when setting out the terms of engagement and participation.
- Eliminating possible barriers that could undermine or prevent participation.
- Ensuring openness and transparency of participation process.
- Supporting all concerned groups to participate including the most marginalised.
- Providing concerned persons with access to information that allows them to understand and evaluate the issues in the decision-making process and provide meaningful inputs.
- Providing reasonable opportunity to influence decision-making and at minima providing feedback on what proposals have been considered and why (or why not).

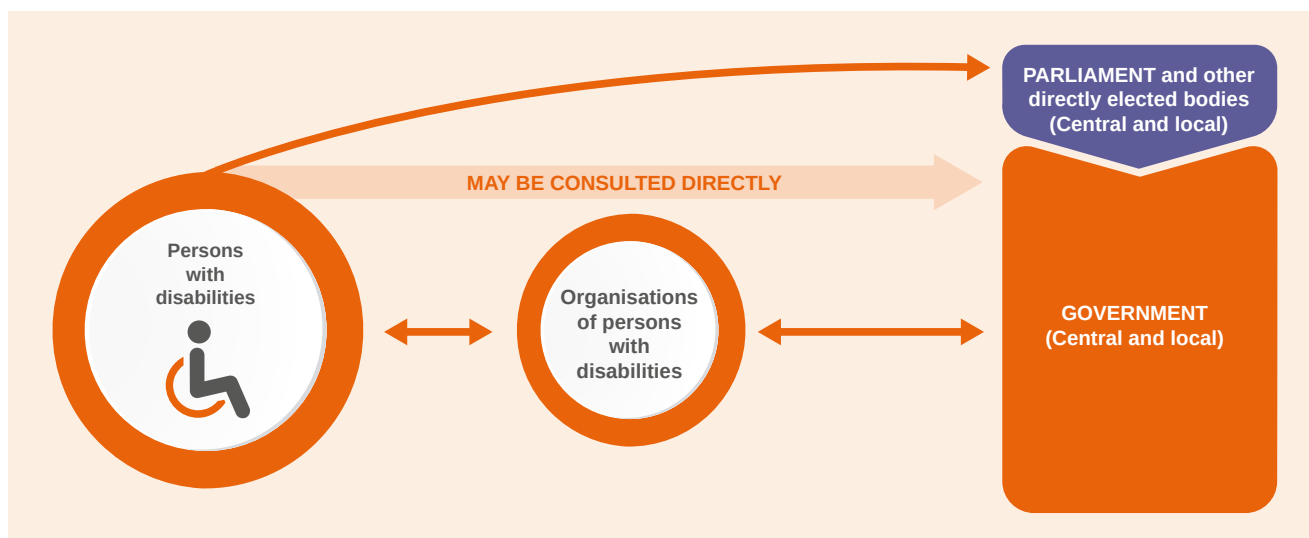
A key element is therefore the creation and maintenance of an enabling environment for effective and meaningful participation of all people concerned.

In addition, with regards to persons with disabilities, the CRPD has stipulated more specific elements in relation to the scope, the process and the organizations of persons with disabilities, which have been explained in the CRPD committee general comment 7 (GC 7).

- The scope of the obligation to “closely consult with and actively involve persons with disabilities” covers the full range of legislative, administrative and other measures that may directly or indirectly impact the rights of persons with disabilities. It also includes public budgeting processes and international cooperation. This obligation applies at all levels (local, national, regional, international) across all sectors.

- ‘Persons with disabilities’ means all persons with disabilities representing the wide diversity in actual or perceived impairments and chronic conditions, as well as sex, gender identity, age, ethnic origin, location, religion, language...
- Process:
 - » All persons with disabilities have the right to vote and to be nominated or elected to any representative and public bodies
 - » Access to information in accessible formats at all stages of participation as well as accessibility of all related facilities
 - » Provision of support of different kind, including peer support or supported decision making, to ensure that all persons with disabilities are in position to take part
 - » Procedures related to participation process should be discussed and agreed so that they respond to the diversity of persons with disabilities
 - » Participation process should provide with reasonable and realistic timelines considering the nature of the organizations of persons with disabilities
 - » Authorities should take into account inputs from all groups of persons with disabilities through their representative organisations in their policies and decisions and duly inform them of the outcomes of consultation and negotiations

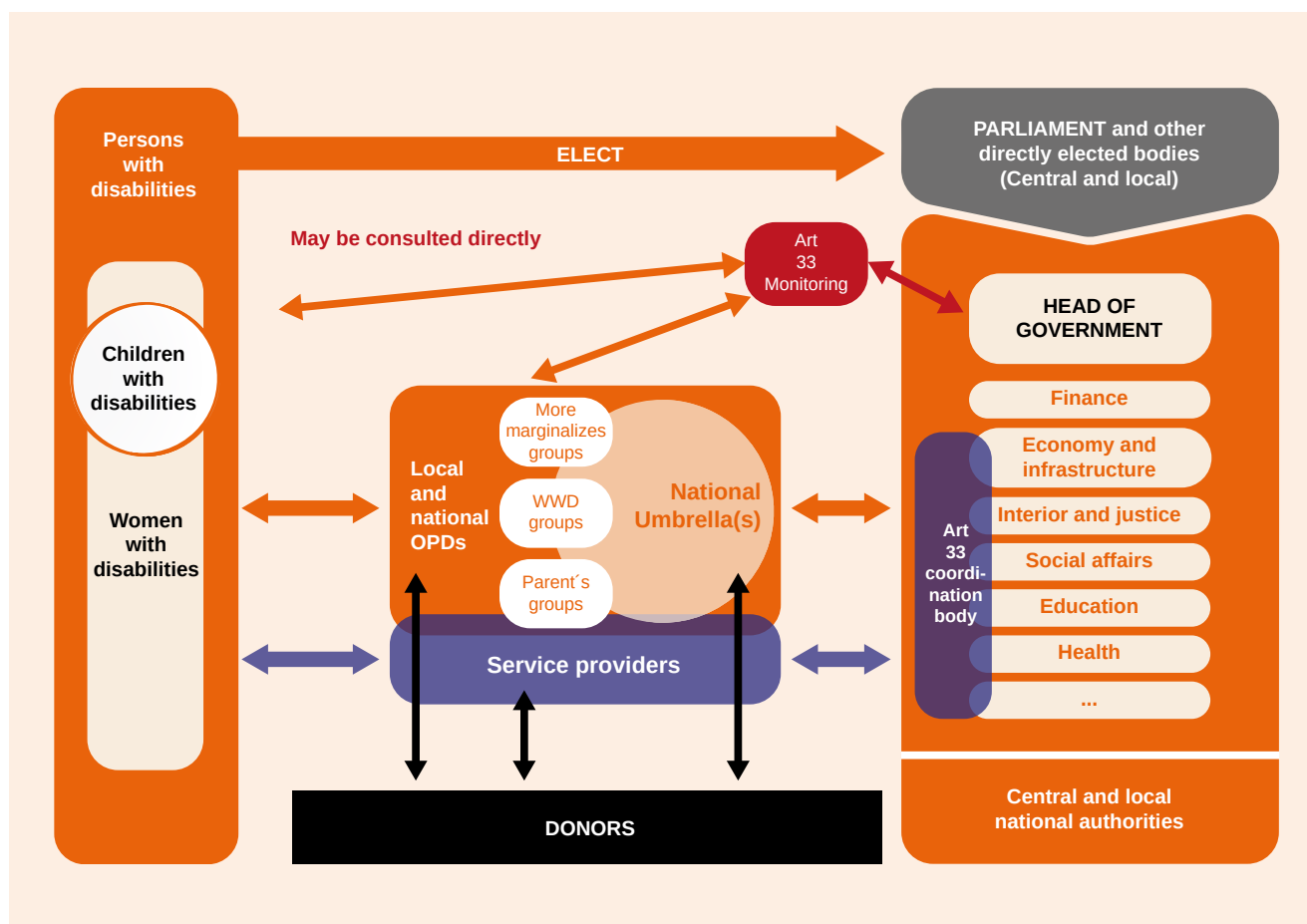
In substance, the CRPD clearly establishes OPDs as intermediary bodies between policy makers and persons with disabilities. A cursory reading of art.4.3 could be visualized as follows:



¹Based on OHCHR guidelines, Special Rapporteur on the human right to safe drinking water and sanitation report, special rapporteur on rights of persons with disabilities and CRPD committee GC 7

"including but not limited to women, older persons, children, those requiring high levels of support, victims of landmines, migrants, refugees, asylum seekers, internally displaced persons, undocumented and stateless persons, persons with actual or perceived psychosocial impairments, persons with intellectual disabilities, neurodiverse persons, including those with autism or dementia, persons with albinism, permanent physical impairments, chronic pain, leprosy and visual impairments and persons who are deaf, deafblind or otherwise hearing-impaired and/or those living with HIV/AIDS, (...) persons with disabilities with a specific sexual orientation and/or gender identity, intersex persons with disabilities, and persons with disabilities belonging to indigenous peoples, national, ethnic, religious or linguistic minorities, and those living in rural areas".

A detailed reading of GC 7 reveals a certain complexity that the scheme below captures only partially:



The GC7 also clarifies the duties of government in supporting Organizations of persons with disabilities (OPDs) with, among others, the following elements:

- All groups of persons with disabilities should have the rights and be able to register easily and freely as formal organisations as well as seek and secure funds and resources from national and international, public and private donors.
- OPDs are a specific type of civil society organization and should be distinguished from others, such as organisation for persons with disabilities.
- Precedence should be given to the opinions and views of OPDs when addressing issues directly related to persons with disabilities.
- States have to ensure access to adequate funding mechanisms, including public funding and international cooperation, and the provision of support, including technical assistance, for empowerment and capacity-building of OPDs' while guaranteeing their independence and autonomy from the State.
 - » Prioritizing resources to organizations of persons with disabilities that focus primarily on advocacy for disability rights
 - » Allocating specific funds for organizations of women with disabilities and children with disabilities
 - » Ensuring that funds are available for different organizations of persons with disabilities in a way that favours their sustainability and capacity to participate, including to self-advocate groups who cannot register due to restriction related to legal capacity

- Encouraging the establishment of a single, united and diverse representative coalition of organizations of persons with disabilities that is inclusive of all the disability constituencies and respectful of their diversity and parity.
- Preventing interference with the right of participation in decision-making processes of persons with disabilities by third parties, such as service providers.
- Establishing mechanisms and procedures, at different branches and levels of Government, to explicitly consider the views of OPDs. This includes permanent consultation mechanisms such as national disability councils.
- Define in close consultation with organizations of persons with disabilities verifiable indicators for good participation.

The broader discussion

The obligations set out by the CRPD and elaborated upon by the committee for States to ensure meaningful participation are very comprehensive and combine regulatory frameworks, institutional mechanisms, financial support, and technical assistance to OPDs. The assumption of the study is that such combinations, if not implemented in good faith and in the spirit of “transparency, mutual respect, meaningful dialogue and a sincere aim to reach a collective agreement on procedures that respond to the diversity of persons with disabilities” as specified by GC 7, could foster strong co-optation by State.

A review of the general literature on public participation and relationship between States and Civil Society Organizations (CSOs) provide multiple elements to understand the challenges and opportunities of implementation of those standards.

Public participation

“The widespread adoption of the language of participation across a spectrum of institutions, from radical CSOs to local government bodies to the World Bank, raises questions about what exactly this much-used buzzword has come to mean”

(Cornwal, 2008)

Whether academic work or human rights standards related publications, all identify the situation in which participation is a facade and does not contribute to empowerment but actually perpetuates or even reinforces inequalities, either by design or by failing to tackle power asymmetry among those involved. The CRPD general comment stipulates that “States Parties should guarantee that they are not only heard as a mere formality or as a tokenistic approach to consultation”.

There are different ways to understand participation and there have been different typologies attempting to capture the different realities that the word covers.

One of the most used is the 8 rung of the ladder of citizen participation by S. Armstein who identified 3 main categories ranging from:

- » **Citizen control:** when citizen is in a decision-making role
- » **Different degree of tokenism:** when citizen is involved and heard but by design has actually little influence on outcome
- » **Non-participation:** this includes manipulation and does not even attempt to hear citizens' concerns

Another typology commonly used is from the Association for Public Participation (AIP2) which differentiates different participation modalities: inform, consult, involve, collaborate and empower. Those levels can be categorized in 3 main types of processes along a scale of level of shared decision authority: engagement, participation and democratic processes (some level can be part of either one or more processes depending of their true aim). It is interesting to note the difference between engagement, which covers the lowest level of shared decision, and all the others which could be qualified as participation. In other terms, solely informing cannot qualify as participation. Participation implies at minima two-way communication, while higher level of shared decision implies deliberative communication.

Most importantly, involve, collaborate or empower categories can be considered as participation or democratic process depending on the true level of shared decision authority. This partly reflects Petty typology (Cornwall, 2008) which questions the rationale of the state or the donors organising the participation space: is it a means to achieve its own objective in which case participation can be manipulative, passive or functional or is it seen as a right of people concerned in which case it could also be transformative and contribute to empowerment.

Another important element of convergence in the literature is that the requirement for an enabling environment to open or create dialogue spaces and inviting CSOs is a necessary condition but is not enough to ensure meaningful participation. There is need for support, especially for most marginalized groups to develop capacity to engage. Indeed, participatory initiatives and participation mechanisms tend to be premised on the false idea that everyone would want to participate if they could and ignore the fact that people and groups can choose to 'self-exclude' as a result of exclusion they face (Cornwall, 2008) which is more challenging to address. This is of particular importance for persons with disabilities (See *box 1*).

Another point of importance is that “participatory processes can serve to deepen the exclusion of particular groups unless explicit efforts are made to include them” (Cornwall, 2008). The decision of inviting specific actors to take part and not others within the same constituencies or the inherent power dynamics within consultation can bring legitimacy to decision that would impact all members of a given constituency (a local community or a specific population) while the representatives of few groups of this constituencies would actually have had an effective say in the process. This is particularly relevant for groups that may not have capacity to organise and engage.

When considering recent years, ICTs have provided media to facilitate voice of groups and individuals that either were not in reach of usual participation processes and structures or did not recognise themselves in traditional representative organisations and processes. While those ICT enabled voices have had a significant impact in terms of mobilisation or influencing the choice of issues tackled in public spheres, they may have limited capacity to negotiate with authorities about how to resolve those issues (Fox, 2015).

When CSOs somehow seize existing participation space or create new ones to bring a specific issue in the government agenda it is important to consider the level of buy-in within relevant level of government as well as CSO capacity for sustained high level of engagement because of the lengthy process design/reform and implementation and evaluation of policies. This implies also that CSOs have a good understanding of policy making and implementation process in their countries (Chowdhury, 2006).

Box 1: Self-exclusion as a legacy of discrimination against persons with disabilities

In many contexts, there are questions about the ability of OPDs to enable the engagement of the most marginalized groups within persons with disabilities. While one may question what a reasonable benchmark across other social movements is, it is undeniable that having experienced long term exclusion and lack of support and opportunities for social interaction and community participation, persons with disabilities are less likely to participate even in in-home activities or family decisions (Gupta, Witte & Meershoek, 2019) and less likely to exert their citizenship as compared to the non-disabled persons (Young, 2016). This lack of participation and their absence from a full range of local and national policy decisions impact their lives directly or indirectly (GC 7) and perpetuate further discrimination. Common issues identified include the negative public attitudes towards people with disabilities, lack of resources to participate, lack of physical accessibility and accessibility of information and communication systems, and the lower level of education of persons with disabilities (Sackey, 2015).

The issue of self-exclusion (Cornwall, 2008) is particularly relevant for persons with disabilities who, as a result of long term exclusion and stigma, may have lesser sense of belonging to a community and thus may have little inclination to spend time on 'community' affairs (Gupta et al, 2019) which can lead to a vicious circle of 'self-exclusion'. Unless specific attention is paid to counter the different reasons for self-exclusion by persons with disabilities in the participation processes and mechanisms, it is unlikely that their presence would improve, reinforcing the self-exclusionary practices further. These reasons often stem from a social, economic, environmental and cultural setup that people live in and may include among others:

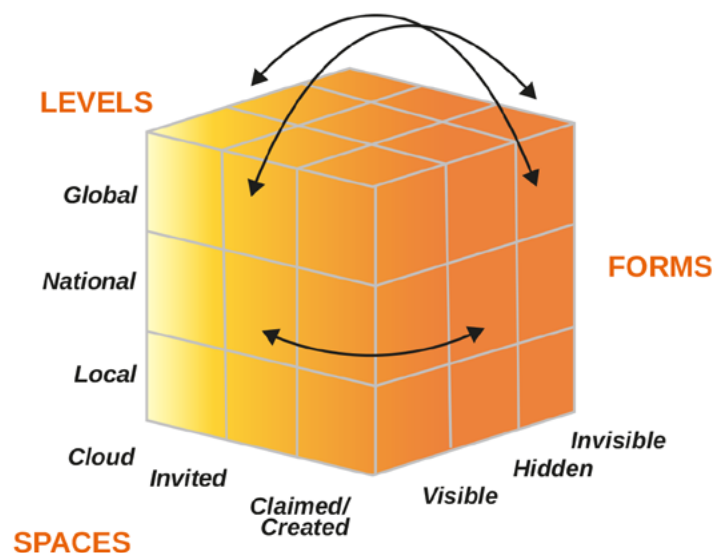
- Internalization of low expectation: in many contexts, persons with disabilities are rarely expected to build a life away from their families and thus are often not expected to have any opinion on community affairs. Further internalizing such low expectations, persons with disabilities adapt themselves to becoming passive recipients and may not have the confidence to engage (Gupta et al., 2018; Sen, 2009).
- Lack of trust and confidence in institutions or even in the mere fact that positive change may be achievable through participation which leads to the perception that the economic, social or psychological opportunity costs of participating may not be worth. This is true for many groups but may be magnified for persons with disabilities.

- Lack of identification with advocacy issues: even with a certain access to information, more marginalized groups of persons with disabilities may not identify with the advocacy issues put forward by lead.

Those are challenging issues to address for OPDs. As for other civic movements, most OPDs are based in the main cities and, within their limited resources, primarily seek to address issues faced by their urban constituencies (higher education, employment in government and corporate sectors, concessions and accessibility to services and public places) to whom they are directly accountable. The issue is that proximity to political space, and, often higher education and social status of OPDs leaders from cities, amplifies their issues and may leave voices of persons with disabilities who live in rural and remote areas unheard (Bezinna, 2019; Bhambani, 2018; Deepak et al, 2013; Kumaran, 2011). This often leads to non-identification of certain groups with the demands made on their behalf which results in self-exclusion. Similarly, women with disabilities or other specific disability groups such as persons with intellectual disabilities, psychosocial disabilities or deafblind.

Participation and power

As mentioned earlier, opening or creating participation space does not equate meaningful participation, let alone effective changes for concerned population. A lot depends on the power dynamics around and within those spaces and processes. A generic model (Gaventa, 2006), the power cube has been widely used when considering advocacy and empowerment dynamic and is very relevant for work on participation.



The power cube is a 3 dimensions model considering the space for participation, the place and level of participation and the form of power considered:

- **Spaces:**
 - » **Closed space:** those are the spaces where decisions are made by authorities without participation.

- » **Invited:** those are the spaces where civil society is invited by authorities to participate with various set of rules and margin for influence.
 - » **Claimed:** those are the spaces claimed by the less powerful parties against authorities.
- **Places and levels for participation:**
 - » This looks at how and by whom the public spaces for participation are shaped and the levels where critical social, political and economic power resides which can be local, national and global.
- **Forms and visibility of power across spaces and places:**
 - » **Visible power:** this is about the most visible and definable aspects of political power such as the formal rules, structures, authorities, institutions and procedures, and process of decision making.
 - » **Hidden power:** This is about stakeholders who exert influence in a covert way not only on outcomes but also on what is set in the agenda and who is taking part in decision making.
 - » **Invisible power:** “invisible power shapes the psychological and ideological boundaries of participation. Significant problems and issues are not only kept from the decision-making table, but also from the minds and consciousness of the different players involved, even those directly affected by the problem” (ibid). The paradigm used by different stakeholders to consider issues of persons with disabilities, the prejudice within and outside the disability movement about specific groups having considerable impact on what and how issues are discussed within different participation spaces and processes.

State-CSOs relationship

Considering that OPDs are civil society organizations and by nature an intermediary body between authorities and persons with disabilities, understanding different types of relations that can exist between states and CSOs is essential when analysing the level and quality of participation. In most countries, CSOs are simultaneously playing a wide range of roles: voice for the poor and marginalized groups in policy design process, engaging as a partner of state in service delivery for the poor or substitute altogether where fragile states are generally recognized as those lacking the capacity or political will to provide basic services to their people, being a watchdog of the same state with regards to issues ranging from public expenditures to respect of human rights, while being also considered as a vector for democratisation by key donors. Hence, CSOs should be able to combine strategies, advocating for change (Voice) and compensating state and market failures (Exit) (Hirschman, 1970). In many countries OPDs may indeed to a certain extent combine those different roles and strategies. These roles imply not only different type of structure, leadership, skills, and means but also different strategies and relationship with the government and public institutions.

A growing literature on relationship between the CSOs and the state argues that CSOs develop their strategies in specific context and conditions, government openness and strategies being some of the most important (Teamey, 2007). The state defines the legal framework for the registration of CSOs and therefore has a strong ability to facilitate or constraint CSOs sector development by tightening administrative procedures or limiting access to international funding. Hence the government by its legal and resource leverage but also because of its duty from the perspective of CSOs is a central element of their work. Their relationship with the state could be adversarial, when CSOs focus on advocacy and greater accountability; supplementary when they fill the gap; and complementary when providing services and being supported by the state to do so (Young, 2000).

Other multidimensional typologies have been proposed to understand these relations. Brinkerhoff (2002) proposes a typology of partnership based on two dimensions: mutuality (interdependence, commitment and power balance) and organizational identity (core values, constituencies and mission). Partnership requires high level of mutuality and strong organizational identity; a relation with lower level of mutuality would instead be considered as contracting by the strongest of the two parties; low level of both organizational identity and mutuality would be de facto extension of the state, while gradual co-optation and loss of autonomy would happen when CSOs have a weak organizational identity (constituencies) but have initially strong agreement on means and strategy.

Najam (2000) develops a typology based on convergence or divergence between CSOs and government on goals (ends) to reach and strategy (means) to reach them. Similar ends and means would lead to cooperation, similar ends and dissimilar strategies to complementarity, similar strategies but dissimilar goals to co-optation, and both dissimilar means and end to confrontation. This typology doesn't assume power balance but considers perceived threat from either CSOs or government. In absence of perceived threat and if means and ends are similar, a scope for cooperation exist. While confrontation echoed with other typologies, complementarity in this model unlike in Coston (1998) and Young (2000) does not assume that CSOs perform and Government pays but refer to "supplementary" as providing services is integral to the mandate of CSOs doing so. Furthermore Najam (2000) assumes that both CSOs and Government while having similar strategies might want to influence and change one another goals therefore co-optation might be at the advantage of both CSOs and state.

Najam (2000) insists on the fact that "even where government is the dominant and dominating institutional player, the ultimate nature of this relationship is a strategic institutional decision made by both the Government and the Non-Governmental Organizations (NGOs)". Considering the multiple roles of CSOs especially as not only actor but indicator of good governance for national stakeholders and international organizations, even if most of the time they have fewer option than states, their decision to engage or to stay in a sector or policy matter, is in itself a strategic decision.

CSOs develop different strategies towards the State depending on their agreement with policy goals and strategies, the degree of acceptance and openness of state towards pluralism as well as the strength of organizational identity and power

balance between the State and CSOs. We might also consider that CSOs tend, as any organization, to set their goals according to resources available to them and to what seems to be realistic and feasible in their environment.

In this regard, international cooperation actors play a significant role. CSOs have been a key element to the overall governance agenda besides public institution capacity building. The international community developed multiple tools such as different democracy assistance programs from USAID, DFID or the European Union among others. The fact is that the multifaceted good governance agenda attributes a lot of qualities and responsibilities to civil society, considered as the third key component of society somewhere between the state and the market (Swyngedouw, 2005). The increasing development of, and support to CSOs especially in the 1990s-2000, was a result of the acknowledgement of both some states and market failure (Najam, 2000). This perspective is also a critical element to consider when analysing public participation in LMICs. Donors priorities, approach to program identification and planning, and funding modality overall can have significant impact on public participation processes. It can influence the way processes are held, who takes part and the subject tackled (Chowdhury, 2006).

Impact of the shrinking of civic space

One of the core demands and arguments of IDA or the CRPD committee is that “Inclusive development requires respect for the active role of organisations of persons with disabilities as key stakeholders to reflect the views of the diversity of persons with disabilities, and orient efforts in compliance with human rights obligations.” As mentioned, while there is a growing momentum for engagement with OPDs, there are also general concerns about the shrinking of civic space. According to Civicus monitor (2019), in all partner countries considered (Burkina Faso, Ecuador, Ethiopia, Paraguay and Sudan) civic space is either:

- Closed – Sudan
- Repressed – Ethiopia
- Obstructed – Burkina and Paraguay
- Narrowed – Ecuador

Recent study on the impact of shrinking civic space on inclusive development (Hossain, 2018) shows that civic space has somewhat changed more than shrunk along several lines:

- Regulations of the civil society organizations especially with regards to governance and funding, which are not all unwelcome, although new restrictions affect aid supported groups disproportionately
- Many civil society actors having to enter closer relationships with political elites or the state, in order to continue to operate
- The human rights liberal framing of advocacy and arguments has faced backlash with “right wing, extremist, and neo-traditionalist groups and urban protest

movements having occupied demonstrably more of the civic space in the past decade”

- Rapid growth of the digital public sphere through social media has dramatically reshaped the civic space for all actors, while more populist groups might have made more effective use of it in the long term

Another important element is that few countries with fairly limited civic space have achieved significant economic growth and human development while others with stronger formal democratic space and a more independent civil society did not manage to overcome political vested interest opposed to redistributive policies. This indicates that the outcome of civil society participation in inclusive development is more related to the overall political settlement and the fit between the state and civil society. Contribution of civil society to inclusive development implies both capacity of CSOs to articulate demands of marginalized groups and a certain level of willingness and ability of authorities to develop related policy response.

1.3 Data collection

After the review of country relevant documentation both on disability and political context, the data collection was based on interviews and exchanges with key informants from OPDs, government, service providers, mainstream CSOs and international cooperation actors from the 5 countries involved in Bridging the Gap.

Confronted with the uncertainty of the number and diversity of role and position of individuals that could be interviewed, rather than developing strict questionnaire, the interviews were guided by a set of questions directed to each group of stakeholders contributing information to the key issues assessed. This guide was elaborated on the basis of the GC7 and the literature review.

Three country missions were carried out (Paraguay, Ecuador and Ethiopia) while calls and emails exchange were used for Burkina Faso and Sudan as security issues prevented in-country work. It is to be noted that the diversity and numbers of key informants varied between countries, with lesser access to Burkina Faso and Sudan. This has limited the scope and depth of the comparative analysis and the possibility to write similarly developed country report. (For more information about the data collection see annex)

Number of stakeholders contributing	Burkina Faso	Ecuador	Ethiopia	Paraguay	Sudan
Non-participation	3	3	5	4	5
Individual activists		2		3	
Service providers (NGOs)		5	2	7	
Other CSOs		1		1	
Government, central and local	1	6	3	5	
International cooperation actors	1	3	3	5	

All the country specific information, collected and summarised by consultants, was then reviewed to carry out a first comparison of key issues related to states obligations, OPDs engagement and role of international cooperation actors. Based on this first review and on the literature, a specific framework was developed to map the situation in each country. (See annex 1 for more details)

1.4 Framework for comparative analysis

Both the literature review and interviews with stakeholders in Bridging the Gap supported countries highlighted the fact that participation is a coproduction between state and the disability movement, while acknowledging that it is influenced by other actors such as service providers and International cooperation actors. For the purpose of the study an analytical tool has been developed which seeks to capture different type of relation and level of participation.

Building on the GC7 and OHCHR guidelines on public participation as well as different models presented in the conceptual framework, it is composed of two axes: State engagement and disability movement strength:

- **State engagement combines elements of:**
 - » Willingness to engage with persons with disabilities: Persons with disabilities are considered a key stakeholder by authorities. This does not equate quality or quantity in terms of consultation.
 - » Development of policies and allocation of resources dedicated to inclusion of persons with disabilities. This is an important element as there is little participation possible without object to inform, consult or involve.
 - » Consultation mechanisms: legal standing, composition, representativeness, frequency of meeting, perceived impact.
 - » Transparency: consultations procedures and process, available data, and budgeting process are transparent accessibility of information.
 - » Level and quality of participation: actual influence of persons with disabilities on public policies and programs (information, consultation, involvement, collaboration and co-decisions).
 - » Support to OPDs: easiness of registration process, financial and technical support.
 - » Inclusive efforts: extent to which different groups of persons with disabilities, including children, women and most marginalized are involved in state enabled participation.

- **Disability movement engagement combines elements of:**
 - » Independence of OPDs (institutional capacities, freedom of speech and

opinion, autonomy of decisions and governance), priorities (advocacy, awareness raising, service deliver), CRPD compliance of key asks, collective action capacities and cohesion as well as inclusion of the diversity of groups of persons with disabilities including gender, children, poorer people and those living in remote location.

The study considers that the level and quality of participation achieved its function of the level and quality of the engagement of both public authorities and OPDs. The level and quality of state engagement is dependent on the strength of the disability movement and vice versa. The movement will not thrive to the optimum level of development in an environment with little state engagement as it will face significant resource limitations and lack of purpose. Also, if government does not put in place minimum policies to address preconditions for inclusion (accessibility, assistive devices, support services, social protection etc), many persons with disabilities will not be in the position to engage. The lack of responsiveness of authorities can also be discouraging and lead to self-exclusion. Similarly, if OPDs and the movement are not organized, inclusive and in position to articulate shorter and longer term demands across sectors and ministries, it will not push government to progressively and sustainably increase engagement and the relevance and impact of consultation mechanisms among others. In addition, the study looked at the level of support of international cooperation to OPDs as well as at support dialogue.

It recognizes that all forward engagement does not equate participation. It, therefore, identifies 11 different stylised forms of interaction which may or may not be qualified as participation. Depending on that the overall governance context but also historical factors, the evolution of relation between State and the disability movement can take different trajectories and can be OPDs driven, State driven or co-produced. However, those trajectories are not linear and can change dramatically depending on the political context and leadership both within government and the disability movement, among other element.

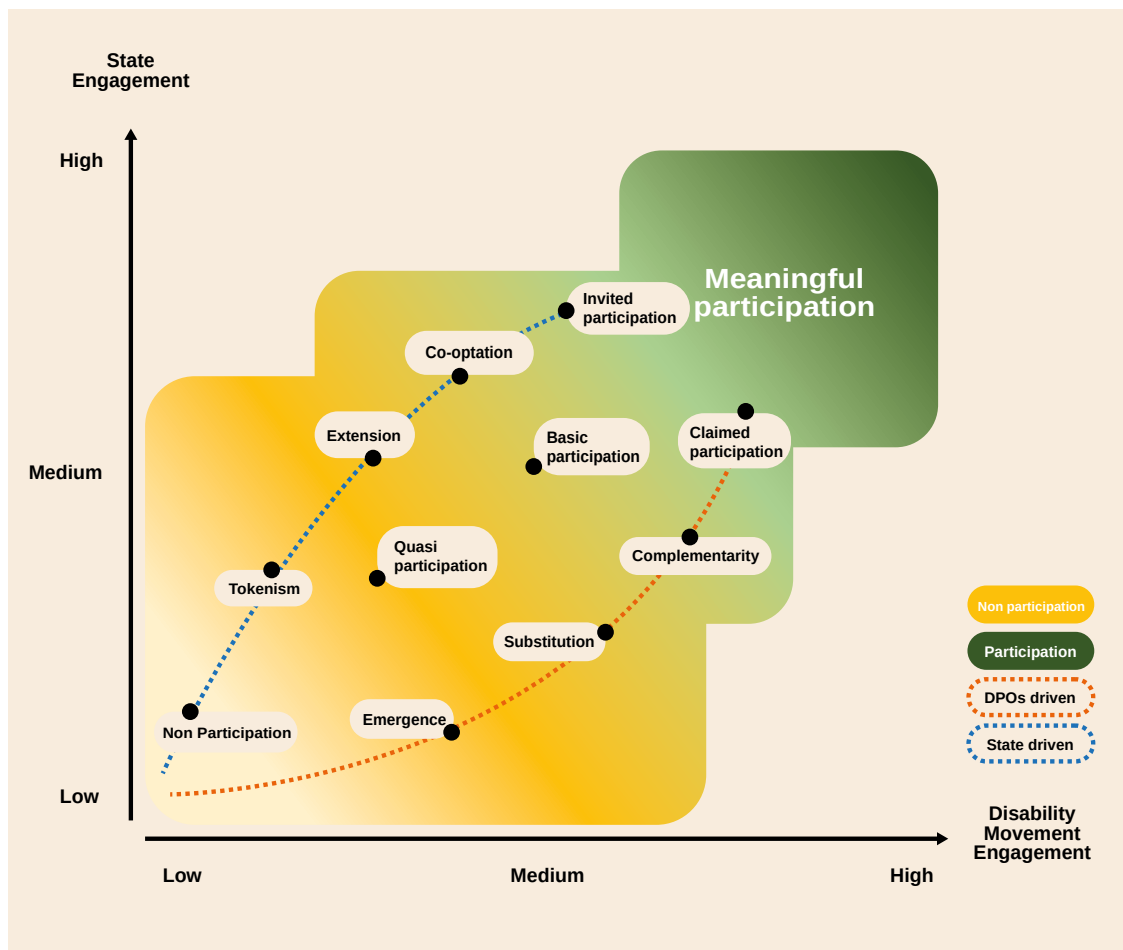
	State Driven	OPDs Driven	Balanced
Non-participation	Tokenism Extension	Emergence Substitution	
	Co-optation	Complementarity	Quasi-Participation
Participation	Invited participation	Claimed participation	Basic participation Meaningful participation

- **State driven:**

- » **Tokenism:** Authorities appear with individuals with disabilities or with few of existing OPDs of their choice with no real interaction in terms of information, consultation or support.

- » **Extension:** Authorities develop formal consultation mechanisms, with little involvement of another ministry than the nodal ministry. They may provide some support to OPDs who align with them and validate and/or implement government decisions. Other actors may have more influence. Part of OPDs leadership may be integrated in state apparatus.
 - » **Co-optation:** Authorities have formal consultation mechanisms in place, with some cross sector/ministries influence, significant policies and resources allocated, and provide significant support to fairly strong individual OPDs. However, OPDs have little collective capacity to influence government decisions and end up validating and/or implementing those decisions. Part of OPDs leadership may be integrated in state apparatus.
 - » **Invited participation:** Authorities have active formal consultation mechanisms, with cross sector/ministries involvement, and are developing and resourcing policies. They do provide support to OPDs, give them primary role, try to reach out marginalized groups, and genuinely seek their views on proposed policies. OPDs are fairly developed and independent but do not yet have the collective and inclusive strength to set agenda and are mostly in reaction to government propositions and priorities.
- **OPDs driven:**
 - » **Emergence:** Public authorities have very low engagement and little to no policies in place or in plan. The disability movement is nascent with few OPDs and low collective action. They concentrate on self-help and awareness raising.
 - » **Substitution:** Public authorities have very low engagement and little policies in place or in plan. There are more OPDs and collective action is increasing but limited. Their focus is increasingly on service delivery and fundraising to compensate for the lack of support and services.
 - » **Complementarity:** OPDs are quite strong and have developed both individual and collective action capacities, and the disability movement is increasingly inclusive. They are focused on support to their members and service delivery. State has somewhat increased engagement and support to certain projects and services proposed by OPDs. There may be formal consultation mechanisms, but there is no actual discussion on State's policies or lack thereof.
 - » **Claimed participation:** OPDs are quite strong and have developed both individual and collective capacities, and the disability movement is increasingly inclusive. They are focused on advocacy towards authorities, with coordinated voice and propositions and make use of all possible spaces, especially those open by international cooperation. Formal consultation mechanisms exist but with low cross sectoral/ministries involvement. State has somewhat increased engagement and are somehow open to consultation to a certain extent but has not a clear agenda.

- **Balanced** (This does not imply positive situation but rather that state and OPDs are equally contributing or equally not contributing to build and fuel participation process):
 - » **Quasi Participation:** State has little policies in place or in plan, formal consultation mechanisms are in place and are somewhat active but with low cross sectoral/ministries involvement and little impact on policy and resource allocation. There are multiple OPDs but still low-level collective action and coordinated voice and they do not have actual influence.
 - » **Basic participation:** State is increasing engagement and starting to develop policies, but with quite limited resources. Formal consultation mechanisms are in place and are somewhat active with limited scope of work and some impact of nodal ministry policy but low level of cross sectoral/ministries involvement. Little support is provided to OPDs. The movement still has limited collective action capacities and lacks inclusiveness but is increasingly using space available, including related to international cooperation.
 - » **Meaningful Participation:** State has strong engagement, with significant policies and resources in place, and it provides significant support to OPDs. Consultation mechanisms are effective with cross sector/ministries involvement, and transparency of information. The disability movement has strong collective, is inclusive and in position to articulate advanced policy proposal and provide informed comment on policy proposed by authorities.



Part 2: The unsteady path towards meaningful participation of OPDs in Bridging the Gap supported countries

2.1 Are Bridging the Gap countries fostering enabling environment for public and citizen participation?

	Burkina Faso	Ethiopia	Ecuador	Paraguay	Sudan
WB governance voice and accountability (n=192)	98	176	111	106	189
CIVICUS civic space monitor as of November 2019	Obstructed	Repressed	Narrowed	Obstructed	Closed

Overall, these countries can be divided in two with Sudan and Ethiopia considered repressed or closed civic space, but with recent dramatic political changes, and Paraguay, Ecuador and Burkina Faso with more openness and possibility for citizen actions.

With the exception of Burkina Faso, they are all below their region's average with regards to the World Bank voice and accountability indicators and none are considered to have an open civic space by the CIVICUS monitor of civic space conditions.

While Burkina Faso was considered in 2013 by the CIVICUS enabling environment index as the nation with the best socio-cultural environment for civil society on the African continent, in the recent years, growing political tensions, precarious security situation with a sharp rise of violent armed conflicts and terrorist threats contribute to make the political landscape challenging.

Ecuador and Paraguay have not so restrictive environment, but in both countries there are political tension, significant inequalities, including with indigenous communities as illustrated by recent clashes in Ecuador.

In the last decade, civic space in Ethiopia has been severely restricted. In 2013, it was considered by CIVICUS index in the bottom 10 countries in terms of enabling governance. In particular, the Charities and Societies Proclamation adopted in 2009 (the '2009 Proclamation') requiring the organisations working on human rights advocacy not to raise more than 10% of their budget from foreign sources had a severe effect on the Ethiopian civil society make-up. In the last two years, change of political leadership has introduced significant changes and openings, but with still uncertain outcomes.

Sudan is also characterised by a highly restrictive civic space, internal conflicts and a sombre human rights record. The 2019 Sudanese revolution leading up to the overthrow of the government and the beginning of a democratic transition has destabilized the country with hopes of opening, but also with uncertain outcomes.

2.2 Review of key components required to ensure meaningful participation

Different elements extracted from the normative framework have been assessed based on the perception by stakeholders. This is not an objective evaluation, which would have required different methodology and resources. While the GC7 provide a benchmark, it is a comparative assessment within the set of countries and level have been assigned after reviewing all countries.

Each element has been assessed with 6 coloured levels: the 3 shades of orange qualify levels considered below the threshold required to ensure meaningful participation and the 3 shades of green qualify levels considered above the threshold. The darker the shade the higher/lower the level.

	Burkina Faso	Ethiopia	Sudan	Ecuador	Paraguay
WILLINGNESS TO ENGAGE (Persons with disabilities are considered a key stakeholder by authorities)					
DEVELOPMENT OF POLICIES for inclusion of persons with disabilities					
CONSULTATION MECHANISMS (legal standing, composition, perceived impact, representativeness)					
TRANSPARENCY (procedures and process, accessibility of information, data,)					
LEVEL OF PARTICIPATION: (inform, consult, involve, collaborate and co-decision)					
SUPPORT TO OPDs (registration, funding, training, in-kind support)					
INCLUSION EFFORTS (type of disabilities, children, gender, location. Ethnic minority)					
DISABILITY MOVEMENT ENGAGEMENT (independence, priorities, inclusiveness, cohesion)					
INTERNATIONAL COOPERATION SUPPORT TO OPDS					
INTERNATIONAL COOPERATION SUPPORT TO DIALOGUE					

a. Willingness to engage (Persons with disabilities are considered a key stakeholder by authorities)

	Burkina Faso	Ethiopia	Sudan	Ecuador	Paraguay
WILLINGNESS TO ENGAGE					

In the 5 countries, there was a willingness to engage with persons with disabilities as stakeholders, in different forms. It seems that in all countries the requirement to consult with OPDs is considered. The fact that the study estimates that all countries have passed the minimum threshold does not imply that there is quality of engagement and ultimately participation. As noted by a public official in Paraguay:

“The disability sector is the only one – neither women nor indigenous people- for which the law compels the ministers, the vice ministers to sit at the table and we haven’t yet taken advantage of this situation to have an impact and to transform”

It also may not imply that OPDs are the main interlocutors or stakeholders of this engagement including in national consultation mechanisms. In Ecuador, for instance, members of the national council (CONADIS) are individuals selected on “the basis of merit” not on their affiliation and responsibility within OPDs.

In Paraguay, service providers play a critical role in the disability sector and it somehow creates a screen that filters real engagement from the state with OPDs which are not so developed.

The willingness to engage can also be undermined by the division and politics in the disability movement such as in Burkina Faso.

In Ethiopia, while disability consultation mechanisms may not be active or effective per se, the government recognises OPDs’ role and they have been actively involved in the reform of the civil society law in 2018-2019.

b. Development of policies for inclusion of persons with disabilities

	Burkina Faso	Ethiopia	Sudan	Ecuador	Paraguay
DEVELOPMENT OF POLICIES for inclusion of persons with disabilities					

In most countries considered, except Ecuador, there are few policies to ensure inclusion of persons with disabilities across sectors. However, most countries have

attempted to amend their legal framework to implement the CRPD, with Sudan, Burkina Faso, and Ecuador having adopted a disability act or equivalent. All countries have a national plan of action or strategy for persons with disabilities.

In **Burkina Faso**, while there is an initial legal framework centred on the law 012/2010 on promotion and protection of rights of persons with disabilities to address exclusion of persons with disabilities, the low level of public resources and institutional capacities combined with recent political tension severely restricts implementation.

In **Ethiopia**, the country's recent policy documents (SDG, National Growth and Transformation Plan (GTP II 2016 – 2020) refer explicitly to persons with disabilities and the recent creation of the Disability Directorate at the Ministry of Labour and Social Affairs (MoLSA) shows a willingness to do more for inclusion of persons with disabilities, especially with regards to social protection, support (rehabilitation, assistive devices...) and economic empowerment. However, there is a limited legal framework, focused on employment, and resources and service delivery arrangements dedicated to implementation are low.

Paraguay has adopted several laws in the field of accessibility, employment and education but has no comprehensive anti-discrimination provision. National Action Plan for the Rights of Persons with disabilities 2015-2030 is supposed to frame the overall public policies for inclusion. There are limited available support services and there are significant issues and lack of resources allocated for implementation of the policies.

Sudan has amended several legislations to be in line with the CRPD and revised its 2009 Persons with Disabilities Act in 2017, which covers different sectors. There are concerns raised by the CRPD committee about the inclusion of some groups or persons with disabilities, such as those with psychosocial disabilities and issues of women with disabilities. Implementation is still very limited.

Ecuador is internationally acknowledged for its support to persons with disabilities. It has a fairly developed legal framework across sectors, with allocation of resources for implementation. Its current president, Mr Lenin Moreno, a person with disabilities himself, was the former special envoy of the UN Secretary-General on disability and accessibility. The main national development plan, the plan Toda Una Vida, 2017-2021 explicitly mentions persons with disabilities and its second National Agenda for Disability Equality, 2017-2021 covers a wide area of action.

c. Consultation mechanisms (legal standing, composition, perceived impact, representativeness)

	Burkina Faso	Ethiopia	Sudan	Ecuador	Paraguay
CONSULTATION MECHANISMS (legal standing, composition, perceived impact, representativeness)					

The 5 countries have all formally put in place consultation mechanisms to engage with persons with disabilities which have most often become the main vector of consultation with OPDs with various level of satisfaction from OPDs. Most national mechanisms are officially under the lead ministry assigned to disability, often the Ministry of social affairs, in Burkina Faso, Paraguay and Ethiopia. In Sudan it has recently been placed legally under the supervision of the President of the Republic. In Ecuador it is an autonomous public entity. All countries have also adopted similar structure at sub national level in the frame of decentralisation, but this has not been reviewed in the frame of this study.

One of the common features across all countries is the fact that while those mechanisms are in place they are not perceived yet as effective consultation mechanisms for different reasons, which can be linked either to membership, lack of resources, actual mandate or lack of influence of the body on policy making and resource allocation across ministries, etc. In several instances, the main issue was that, irrespective of the formal mechanism, influence is granted to those who have connections with individuals inside the state apparatus.

In **Burkina Faso**, the Multisectoral National Council for the Protection and Promotion of the Rights of Persons with Disabilities (COMUD/Handicap) is the national mechanism for follow up and implementation of the CRPD, created within the law 012/2010. Placed in the Ministry of Women, National Solidarity, Family and Humanitarian Action, it is composed of 76 members that include, in addition to the central government's representatives, a trio of the regional governor, the regional director in charge of disability issues and a representative of the regional OPD network from each of the 13 regions of the country. It has a permanent secretariat.

COMUD/Handicap holds one ordinary session a year, and extraordinary sessions are organised from time to time. This set up has been universally criticised by the OPDs for the lack of intermediate follow-up of the decisions taken at the ordinary session and for the lack of any budget to enable participation of regional actors, both regional governments and OPDs (for whom the financial burden of coming to Ouagadougou is significant). As a result, the participation in the meetings of COMUD is inconsistent, and the body is not well known or acknowledged by the stakeholders whom it is supposed to bring together.

Stakeholders also commented that due to the verticality of the governmental structures, the COMUD decisions are largely ignored by the services outside the Ministry of Women. Some OPDs' proposal to transfer the COMUD/Handicap to the Office of Prime Minister to give it more visibility and recognition has not been followed so far.

There is a consensus among the OPDs and other actors that the COMUD, as it is today, does not live up to the intentions of its founders in 2012 nor does it provide yet an effective CRPD-compliant mechanism of consultation.

In **Ethiopia**, the National Implementation and Monitoring Coordinating Committee (NIMCC), set up by a ministerial directive, is composed of representatives of key federal Ministries, OPDs (all of whom are FENAPD and its members), other relevant civil society bodies and chaired by MoLSA (that also provides

the secretariat of the Committee), and is supposed to perform the function of a coordination mechanism for the implementation of the national plan of action on Persons with Disabilities (2012-2021). The structure is officially replicated at the regional levels.

However, the committee has not been identified in the stakeholders' interview as a key mechanism. The MoLSA remains the primary government interface for most OPDs. On some occasions they have contact with the federal parliament and other ministries, such as Ministry of Education but this remains limited due to disability still being seen exclusively as the realm of MoLSA.

In **Sudan**, the National Council for Disabilities is the main coordination and consultation mechanism under the CRPD. The Council was set up by the 2009 Persons with Disabilities Act. It is the main authority for planning, monitoring and coordination authorities for all disability policies. Initially headed by the Minister of Welfare and Social Security, the Council received an upgrade in the 2017 Persons with Disabilities Act and is now under the supervision of the President of the Republic "or whoever he delegates" (Art 5(4)). The Council is constituted of relevant public sector offices and OPDs, the latter making up not less than 50% of members. At present, every nationwide OPD is represented by two persons, including women and young people with disabilities. Individual experts with disabilities are also represented.

Overall, OPD respondents' consensus was that their relationship with the National Disability Council was generally positive; they were also united in the regret that there were not more resources allocated to the work of the Council and its participating OPD members. Indeed, the Council has a small budget for running of its Secretariat and relies on international donors (the Italian and Japanese development agencies in particular) for projects and capacity building activities but this remain limited.

Other structures that have a mandate to work on disability rights issues in Sudan are:

- A subcommittee on persons with disabilities in the National Assembly, which is part of the Health and Housing Committee and is presided over by a member of the National Assembly with a disability
- A 'persons with disabilities' section in the Advisory Council for Human Rights, the president and members of the section being themselves persons with disabilities
- Seventeen provincial councils for persons with disabilities

In **Ecuador**, the National Council for the Equality of Persons with Disabilities (CONADIS) is the main coordination and consultation body and is connected with key government institutions. It is an autonomous public body created under the 1992 law on disability and 2008 regulation. The CONADIS has 23 territorial offices. Under CONADIS, a fairly well resourced technical Secretary has the role "to coordinate and manage comprehensive public policies along with organizations of the Ecuadorian State, civil society and other organisms to guarantee the rights of Persons with Disability" and "to encourage active and organized participation

of Persons with Disability, their families and the community in the creation and application of social policies that guarantee their full integration". Civil society is represented by persons with disabilities representing different groups of persons with disabilities, who are selected on the basis of merit. While the president of CONADIS is also the president of the Federation of persons with physical disabilities, other civil society representative selected may not necessarily represent other OPDs themselves and there is no clarity of what actually the influence of those representatives is.

CONADIS is known by all stakeholders and perceived as the centre of the main decision-making related to disability. Regarding communication with the government at national level, the organizations can address different ministries, but in general they have more impact if they get to them through CONADIS. It has strong influence on the disability movement as it has been a supporter of the creation of the main OPDs federations and also the channel for the main funding to OPDs and it develops the guidelines related to the use of those funds. The 4 main national federations are in the same building as CONADIS.

In **Paraguay**, the National Council on Disability (CONADIS) was created as the main consultation mechanism with civil society, by the Executive Order 10,514 of 2013, which regulates Law 4,720 just after and under the National Secretariat of Human Rights for Persons with disabilities (SENADIS). The representation of civil society is ensured with at least seven elected representatives of organizations of and for persons with disability, representing different groups (persons with visual impairment, persons with hearing impairment, persons with physical impairment, persons with intellectual disability, persons with psycho-social disability, organizations of families with disability and the persons with disability which represent the interior of the country). The representatives are elected by all the organizations which are registered in SENADIS and the election is monitored by the Electoral Court. This is a key difference with other countries reviewed. One of the key issues about CONADIS' membership regulation is that SENADIS does not differentiate between organization of and for persons with disabilities which has led CONADIS to be strongly influenced by service providers. As in Ecuador, all the actors interviewed know that the disability representation structure at national level is formed by CONADIS. While it's perceived positively and an important step forward, stakeholders are not always clear about its role and effectiveness and think that more resources are necessary for it to work better.

CONADIS is led by the government minister from SENADIS (National Disability Ministry) and other important government areas are a part of it.

Similar structure also exists at sub national level with the CODEDIS (Departmental Council on Disability) and in some cases, the COMUDIS (Municipal Council on disability).

d. Transparency (procedures and process, accessibility of information, data)

	Burkina Faso	Ethiopia	Sudan	Ecuador	Paraguay
TRANSPARENCY (procedures and process, accessibility of information, data,)					

Across the 5 countries, OPDs are adamant that there are significant issues around the lack of transparency and access to information in general. It is perceived as a fundamental barrier to their participation and engagement.

Another issue is the lack of transparency of processes in the preparation of laws or programs and even more in the planning of budget allocations, including in providing grants for organisations.

There was reference to the fact that meetings were taking place in an inaccessible building (Burkina Faso) or that adequate provision of sign language interpretation is rare (Sudan).

The growing use of social media as a mode of communication is on the one hand helpful but also a concern due to accessibility issues and the fact that it excludes those who do not have access to ICTs, who are usually groups that are already marginalized either due to accessibility, poverty, language, remote areas etc.

While there have been uneven attempts to ensure accessibility of meetings and making information available in accessible format, it is not achieved in a steady way.

e. Level of participation: (inform, consult, involve, collaborate and decision)

	Burkina Faso	Ethiopia	Sudan	Ecuador	Paraguay
LEVEL OF PARTICIPATION: (inform, consult, involve, collaborate and co-decision)					

After reviewing the situation in different countries, it is fair to say that the level and quality of participation is perceived low in most countries and is not close to being qualified as meaningful. It is patchy and uneven, failing to provide adequate information and carrying consultation that is often seen as ineffective.

An interesting element of the study is that while there is a strong diversity of contexts, the outcome is more or less the same in terms of perception by OPDs. Whether in a country with significant programs and policies such as Ecuador or the one with the least policies in place, Ethiopia, OPDs do not feel that their voices are really taken into account in designing those policies and making decisions.

Multiple elements have been identified as undermining the level and quality of participation:

- As mentioned, the lack of transparency and access to information which also further undermine trust both in institutions and processes.
- Several interviews across countries pointed to the impact of lack of coordination across ministries which undermines vastly the impact of the consultation mechanisms.
- The fact that some consultation mechanisms such as COMUD in Burkina Faso do not have the required institutional capacity and weight to influence other ministries limits the perceived impact of OPDs involvement, even if the consultation was done in good faith.
- Prevailing attitudes of non-acceptance of OPDs (and persons with disabilities in general) as equal partners whose views should be given equal weight. While there is a willingness to engage with persons with disabilities and acceptance of the “nothing about us” principles to different extent in all countries, it does not imply that there is lead in terms of influence. It is for instance obvious that service providers organization in Paraguay have much stronger influence than OPDs.
- Impact of other stakeholders such as service providers.
- The turnover of public administration counterpart which undermines OPDs investment.

In **Ethiopia**, leading national OPDs are well-known and recognised for their expertise. They are regularly invited to consultations and activities organized by the government and other institutional stakeholders. One sector in which OPDs have been actively involved is education. However, some interviewees had significant reservations about the actual impact of OPDs’ interventions.

It is important to note that as part of political ‘thawing’ under the new regime, the 2009 Proclamation was repealed, and the process of drafting the new legislation regulating the work of the civil society commenced in the Prime Minister’s Office. The civil society organisations, including the National OPDs Federation (FENAPD), were invited to give their input to the new law, which they did having first agreed on a joint CSO position. The structure working on the development of the new law consisted of 11 members, two out of whom (one female and one male) represented FENAPD, while others represented different civil society interests (6 members) or government agencies (3 members). The process was facilitated by an international donor that supported the organisation of a hearing between the government and the OPDs. The Organisations of Civil Societies Proclamation No 1113/2019 was speedily agreed on and passed in March 2019.

In **Burkina Faso**, the respondents agreed on the vertical nature of the decision-making processes in the country that directly impacts style and quality of involvement of the civil society, including OPDs. Their participation is not systematic and always needs to be claimed vis-à-vis the authorities that rarely have a natural impulse to reach out to the OPDs. This is particularly felt in the areas outside social affairs or education. Moreover, the OPDs’ requests for meetings usually take a long time to process and often get a negative response (or a meeting with a

junior Ministry staff member unable or incompetent to make a decision on the topic discussed). The interviews highlighted several instances of inadequate involvement of organisations of persons with disabilities in the decision-making processes and the resulting shortcomings of the decisions. Several OPDs respondents observed that the consultation procedure used for the ongoing revision of the Constitution of Burkina Faso, whereby the OPDs were not directly consulted by the Constitutional Committee, did not allow the OPD movement to adequately voice and defend their proposals. Different OPD federations got to sit on a sub-committee that fed the conclusions to the Constitutional Committee, and their views were not considered, which seems in opposition to the attention that the proposals of other civic groups have received.

In **Sudan** while most OPDs respondents observe that the governmental structures are not closed to them per se, they regret the lack of transparency and dependence on the quality of dialogue with the government on personal relations between the OPDs and the institutional stakeholder. Despite multitude of implementations, follow-up and consultation structures, the OPDs noted a significant lack of coordination between different public bodies, their failure to manage information in a transparent and cooperative way and a general difficulty for the OPDs to participate in their work in a meaningful manner. Also, an excessively high level of bureaucracy has been reported - in order to work on a specific issue, the organization must sign a memorandum of understanding with the government agency responsible for the issue, which is a long and labour-intensive process. On the positive side, OPDs have noticed the steps taken by the Council to improve the OPDs' participation in the conception and development of the Council work plan 2020 – 2030 which were prompted by the recommendation made by the CRPD committee to improve participation of persons with disabilities.

In **Ecuador**, civil society organizations interviewed both OPDs and service providers mentioned that they do not have significant influence on the public agenda; they all agree that they learn about resources or policies through the CONADIS website, public announcements or directly through decrees. Consultations do take place and the government will consult them and listen to them and may sometimes take their ideas, but there is no follow-up or further co-elaboration. There is a perception that the government may not trust the civil society.

In **Paraguay**, while CONADIS is perceived as potentially an important body with elected representatives this does not yet foster a strong participation of persons with disabilities. The strong influence of service providers contrasts with the emerging capacities of OPDs. A recurrent comment is that those who succeeded in making contact with someone with influence in the government have been able to have an impact on the public agenda, implying that this impact is not achieved through formal participation.

f. Support to OPDs (registration, funding, training, in-kind support)

	Burkina Faso	Ethiopia	Sudan	Ecuador	Paraguay
SUPPORT TO OPDs (registration, funding, training, in-kind support)					

Except in Ecuador, there is little support provided to OPDs in their registration or functioning. Ethiopia is a specific case with a decade long regulation on CSOs which limited drastically their advocacy possibilities. As seen in the international cooperation section, support from donors and International Non-Governmental Organizations (INGOs) is indispensable to the existence and development of OPDs.

► Registration

In **Ethiopia**, The Charities and Societies Proclamation No 621/2009 adopted in 2009 (the '2009 Proclamation') had the purpose and effect of tightening the civic space in the country by requiring from the organisations working on human rights advocacy not to raise more than 10% of their budget from foreign sources. The organisations who did rely on foreign donors had to register as 'development NGOs' and were prevented from openly conducting advocacy actions. As a result, most of them modified the profile of their work and had to re-register since the Law was changed in 2019 to allow this.

In **Burkina Faso**, the country is characterised by a comparatively liberal attitudes towards the freedom of expression, association and assembly, with few restrictions on the functioning of the civil society, including organisations of persons with disabilities. There are very few procedures required to create an association. While the law provides for the status of 'public benefit associations' for CSOs fulfilling certain criteria, the real value of this status for the two OPDs that hold it is limited.

In **Sudan**, the organisations of persons with disabilities participating in the interviews confirmed that the law does not restrict the creation and registration of NGOs.

In **Ecuador**, the registration required some work, but the interviewees admit that the government made changes and provides aids such as a tutorial which simplifies the registrations and having legal status now is not a problem.

In **Paraguay**, obtaining the legal status is a long process which may require a lawyer to ensure that that it is done properly. It has a cost that not all small organisations can afford, and it seems that it is more difficult for OPDs in the interior of the country. To be registered with SENADIS, organizations need to prove 2 years of existence.

► **Material support (Funding and in-kind support)**

In **Ethiopia**, a pre-defined number of national-level OPDs (members of the Federation of National Associations of Persons with Disabilities, FENAPD) receive a small amount of government funding amounting to about 5% of the OPD annual budget. The government has certain expectations about how this funding should be used by the beneficiaries. As a rule, regional level OPDs do not receive such funding from regional governments. All OPDs are strongly dependent on funding from international donors and national service providers. Many are involved in income-generating activities to cover basic costs of running an office. At the regional levels, OPDs usually do not benefit from regular financial support from the regional governments, which has become a major source of frustration to many of them. In Amhara region, for example, the OPD federation has resorted to income generation activities such as selling merchandise in order to support their activities. The regional Bureau of Labour and Social Affairs suggested that the in-kind support (computers, office space, help in organising events) somewhat compensates for the absence of operating funding for OPDs.

In **Burkina Faso**, while the holders of the “public utility” status are in principle eligible for regular financial support from the state, one of the concerned respondents declared that the association has not received it, the relevant legal provision not having been operationalised by the government.

Associations that are not eligible for financial support under the “public utility” scheme sporadically receive money from the Ministry of Human Rights and Solidarity, but these funds are extremely limited and subject to availability.

In **Sudan**, no individual OPD among those interviewed receives operating funding from the public sources. According to them, access to funding is irregular and based on personal relationship with the Finance Ministry. The organisations receiving financial support are re-evaluated for eligibility on a monthly basis. The lack of sustainability in access to government funding is criticised by all OPDs.

In **Ecuador**, all the 4 OPDs federations, receive fifty thousand dollars annually with some exceptions, (for example, in 2016 due to the earthquake there were federations that did not receive funds) through the MIES (Ministry of Economic and Social Inclusion). They have counted on this budget since the vice-presidency of Mr Lenin Moreno. It was a great growth because, before that, they were receiving between 3 and 5 thousand dollars per year. However, this funding is not guaranteed and can be stopped any year. It is important to mention that these funds that they receive come with some guidelines to work with and in 2019, the federations received common guidelines. One of the issues mentioned was the difficulty to start income generating activities because of the risk to lose the non-profit status. Ecuador was the only country where OPDs mention the range of training provided by CONADIS for OPDs and the fact that they are consulted on the trainings they require.

g. Inclusion (type of disabilities, children, gender, location, ethnic minority)

	Burkina Faso	Ethiopia	Sudan	Ecuador	Paraguay
INCLUSION EFFORTS (type of disabilities, children, gender, location, Ethnic minority)					

All countries include different groups of persons with disabilities in their consultation mechanisms. However, review did not indicate any particular effort to reach out to the most marginalized groups. Paraguayan CONADIS includes in its regulations the obligations to representatives for groups of persons with psychosocial disabilities and persons with disabilities from the interior of the country but it does not ensure that those are persons with disabilities themselves due to the non-differentiation between organizations of and for persons with disabilities.

Similarly, there was evidence of efforts to ensure gender balance in representation and there was no particular effort to consider views of children with disabilities themselves.

h. Disability movement engagement (independence, priorities, inclusiveness, cohesion)

	Burkina Faso	Ethiopia	Sudan	Ecuador	Paraguay
DISABILITY MOVEMENT ENGAGEMENT (independence, priorities, inclusiveness, cohesion)					

The situation of the disability movement is very diverse across the 5 countries. The most structured movement is in Ethiopia, but with little overall focus on advocacy due to political context, while the least structured is in Paraguay with very few OPDs and a national coalition CONAPRODIS overshadowed by strong service providers. Burkina Faso has a proliferation of OPDs at all levels with conflict among different federations.

In all countries there are significant issues in terms of inclusiveness of the movement with regards to most marginalized groups and people living in rural or remote areas and uneven representation of women with disabilities and their issues.

It is interesting to notice that both in Ecuador and Paraguay, there is not a cross disability umbrella OPD federation, as the CONADIS in both countries somehow took this role. Absence of the umbrella seems to limit the capacity of the OPDs to build an autonomous advocacy platform to engage with authorities including through the CONADIS.

Overall, it is interesting to note that OPDs of 2 countries out of 5 did not submit written public submission to the first CRPD committee review which is quite rare. While the non-submission from Ethiopia can be easily understandable considering

the situation in the country at the time, the lack of submission from Ecuador raises questions while public submission from Sudanese OPDs show that they felt relatively safe to do so.

	Burkina Faso	Ethiopia	Ecuador	Paraguay	Sudan
OPD written submission to CRPD committee review	YES	NO	NO	YES (with NGOs)	YES

In **Ethiopia**, there is a nationwide federation (FENAPD) uniting 8 disability-specific associations of persons with disabilities as full members and other organisations working in the field of disability as ordinary or associate members. With Ethiopia being a federal state, this structure is loosely replicated at regional levels. Other disabilities groups are still finding their way to be a part of the movement, and some are still on the outside of the movement. Most OPDs concede that certain groups of persons with disabilities on the ground do not receive enough representation, or even recognition, within the movement. The groups most often mentioned are women and girls with disabilities. The movement of women with disabilities has been an integral part of the OPD umbrella since 2016 and this formal acceptance has not yet been accompanied with meaningful inclusion in all issues. Other groups mentioned include deafblind people (a truly emerging issue with little understanding of it but acceptance to improve it), people with psychosocial disabilities, as well as people with HIV/AIDS, chronic illnesses, refugees with disabilities, etc.

OPDs also acknowledged difficulties in reaching out to people with disabilities in rural areas where disability stereotypes and stigma, more prevalent than in urban areas, result in people with disabilities being hidden from the community and unaccounted for. Additionally, many people with disabilities are likely not to recognise disability-based discrimination when faced with it, thus not triggering the need to reach out to an OPD for advice/support etc.

According to the majority of respondents, the 2009 Proclamation had a devastating effect on the Ethiopian civil society make-up, including national OPDs. Most of them were forced to re-register as 'development NGOs' and significantly change the scope of their work to comply with the new regulations. The membership of FENAPD (a 'development NGO') was altered, with the membership of some of its members (ENAB and ENAPH) that classified themselves as 'advocacy' organisations, being discontinued (they have since been re-admitted). A number of OPDs interviewed implied that they had continued doing some (limited) advocacy work despite the registration restrictions imposed by the 2009 Law labelling it 'awareness-raising' or 'training' to avoid conflicts.

All OPDs interviewed seem to do some advocacy work, however the main impression remained that it was not their core activity. Activist culture being a fairly new concept to the civic society, a lot of OPD energy is spent on securing resources for their functioning, as well as capacity building and service delivery to their members. It addresses the gap left by the inaccessibility of mainstream services and general shortage of disability-specific services provided or supported by the public structures.

In **Burkina Faso**, most respondents have raised the phenomenon of multiplication of associations as a fairly serious problem to proper functioning of the civil society and being taken seriously by the institutional stakeholders. As in other sectors, the disability movement is characterized by a high level of fragmentation and division. There are three competing national platforms: the FEBAH established in 1992, the ReNOH created in 2011 after internal divisions within FEBAH, and the newly formed CNAPH established in 2016. The reasons behind the existing fragmentation lay, according to some, in the leadership problems, associations being driven by personal gains of their leaders instead by the common goal of uniting persons with disabilities and lack of accountability for the funding received from external sources. These respondents voiced their sincere regret at the repeated failures of reunification of the movement. Inside the federations, a certain level of competition for scarce funding also exists between members.

In addition to the challenge related to government mechanisms, it seems that the OPDs' inability to work together and speak in a united voice has hampered their participation, including on issues such as the implementation of the 2012 Law on the Protection and Promotion of the Rights of Persons with Disabilities.

In addition, representation of specific groups in the OPDs remains patchy. While women with disabilities have strong visible organisations, the issues concerning girls and women with disabilities may get drowned in generalist organisations. Reaching out to persons with psychosocial disabilities is difficult due to stigma and the families' unwillingness to expose their members with psychosocial disabilities.

In **Sudan**, the formation of one national federation representing all disabled people's organisations, regardless of the type of impairment, is underway. In 2014, a network of NGOs and OPDs named "Sudan Disability Network" was established. It includes more than 50 organisations active in promoting and protecting the rights of persons with disabilities. The network, which has been supported by international NGOs, is now completing the formal registration process following the Sudanese legislation. As of November 2019, the new federation has not been able to hold its first general assembly due to procedural limitations (some of its founding members' registration certificates were not valid) and lack of budget to organise the meeting. The respondents (interviewed around that time) voiced a concern that the deterioration of the security atmosphere in the country may have negatively impacted their activities.

The organisations working on the rights of people with intellectual disabilities voiced their frustration that the intellectual disability is not well understood or accepted by some other disability organisations, resulting in the organisations of/for people with intellectual disabilities being excluded from the network and having difficulties in accessing resources on an equal footing with others.

In **Ecuador**, there are 5 federations that have offices for hire in the CONADIS building. Four are of persons with disability and their families, representing intellectual disability, deaf persons, blind persons, persons with physical impairment and one is of service provider organizations. Information collected showed that despite their individual capacities, those federations do not have a collective voice. While there were some ideas of building

a confederation, it did not happen and as a result, there is no OPD umbrella organization, this role being somehow appropriated by CONADIS. The very strong link with CONADIS while securing resources to function seems to limit their autonomy and ability to challenge authorities.

From the federation of persons with intellectual disability, it was pointed out that many organizations continue to review the bylaws to become true OPDs as they are led by non-disabled people. They noted that "the first association of people with intellectual disabilities with legal basis, bylaws, and a directory composed only of people with intellectual disabilities was formed in October last year".

In **Paraguay**, the disability sector is dominated by NGOs for persons with disabilities that have historically been working in providing services and raising awareness. There are few national and local OPDs, especially organizations of deaf people and of blind people, but many groups do not have adequate self-representative organizations. The civil society national coordinated body in the disability field is led by service providers.

i. International cooperation support to OPDs

	Burkina Faso	Ethiopia	Sudan	Ecuador	Paraguay
INTERNATIONAL COOPERATION SUPPORT TO OPDS					

In all the countries, it is clear that international cooperation support is critical for OPDs not only for obvious reason of access to basic resources, but also for independence and autonomy reasons. OPDs consider that relation with donors is more balanced than with governments.

However, in several countries OPDs highlighted the lack of clarity, information and ultimately access to IC funds. The level of co-financing or technical capacities to develop proposals and match administrative requirement are significant barriers especially for most marginalized groups.

In **Ethiopia**, generally, the OPDs have a fairly positive experience when working with international donors. Firstly, they are their main source of funding and allow them to work and exist. Secondly, International NGOs working on disabilities are actively consulting OPDs in order to align the different activities and seek coordination among donors working on disability. It appears that donors also give more attention to disability and show interest in supporting OPDs. For instance, FENAPD noticed that USAID in Ethiopia was lagging behind other international donors in disability mainstreaming (notably, DFID). They attempted to address this gap in a meeting with USAID representatives who then committed to systematically include disability in its calls.

In **Burkina Faso**, recent increase of the international stakeholders' contribution to increased attention to the rights of persons with disabilities has been acknowledged by the OPDs. The main sources of income for disability associations remain funding from international NGOs and development agencies. However, since more often than not this funding is linked to specific project activities, the possibilities to develop sustainable advocacy activities according to the association's priorities are fairly limited. At the same time, some donors are trying to take a vocal position concerning the fragmentation of continued weakening of the OPD movement by withdrawing the funding from competing federations and making it conditional on the renewal of reunification attempts. According to some respondents, such tactics could be beneficial to pushing the OPD movement to revisit their cooperation strategies.

In **Sudan**, the importance of international support is also acknowledged as critical for OPDs. The respondents voiced the need for clear guidelines on accessing resources by the disability movement. Without appropriate training and transparency of funding mechanisms, the OPDs find that very few resources are available and accessible to them. Several respondents (National Union of the Physically Disabled, National Blind Association) have noted their past partnership with international disability NGOs, such as ADD International, and the European Union. In most cases, the partnership has now been terminated for various reasons.

In **Ecuador**, federations at national level receive support from international cooperation and considering the way in which they receive funds from the State, this cooperation is very valued by OPDs "because there is a more horizontal relationship and projects are much clearer, much more transparent. This peer-to-peer relationship with common goals is maybe much more evident than the relationship with the ministry".

They highlighted that BtG is the only project in which federations work together. They say: "we have logically different objectives, each one has its own need, there are no internal conflicts between us, each one works independently. We have gathered thanks to the Bridging the Gap project, we have begun working on a common issue, education, which has been the main axis, something we can agree on (...)". Only at national level they mention how important it is that cooperation supports the training of new leaderships that can contribute to government planning to empower organizations of people with disabilities.

In **Paraguay**, the organizations of persons with disabilities say that they do not work directly with major donors but receive funding through other organizations. They mentioned the capacity challenge that limits their abilities to apply for funds and secure international cooperation support directly.

j. International cooperation support to dialogue

	Burkina Faso	Ethiopia	Sudan	Ecuador	Paraguay
INTERNATIONAL COOPERATION SUPPORT TO DIALOGUE					

Stakeholders perspective points to an important role that international cooperation actors can play in facilitating and supporting dialogue between states and OPDs, but they could do more. There are different avenues taken to support such dialogue:

- Direct financial support to national mechanisms, such as in Sudan.
- Support to specific consultative processes, such as in Burkina Faso and Paraguay.
- Fostering dialogue in their programs by inviting and consulting with OPDs and demonstrating value of dialogue and consultation. In Burkina Faso, Sudan and Ethiopia OPDs highlighted the growing interest of donors in disability and the positive impact it has in making the environment more conducive to their advocacy and dialogue with authorities.

In **Ethiopia**, donors' attention to disability issues seems patchy. While some donors are not yet fully aware of the opportunities and obligations created by the CRPD, others are very conscious and increasingly systematically mainstream disability in their work. A good example of support among others is the Disability mainstreaming directive which is currently in the process of being approved by the regional government of Amhara region. Prepared by the Bureau of Labour and Social Affairs (BoLSA) with active participation and support of Light for the World, as well as Bureaus of Justice, Health and Education, disability organisations and the private sector, it will be compulsory for implementation by all 30 sectoral Bureaus/offices of the Amhara government in order to ensure disability-inclusive development.

In **Burkina Faso**, there is a rapid change with most development partners increasingly including a disability component in their work, thus supporting better representation and participation of organisations of persons with disabilities. An interesting initiative was the support of Austrian cooperation through the NGO Light For The World to first CRPD country review by supporting both the preparation of the initial report on the implementation of the CRPD by the government (MFSNFAH) and the preparation of the first alternative report of the civil society on the implementation of the CRPD. Also, activities are coordinated with the network of International NGOs operating in the field of disability represented by the "Cadres de Concertation International" (CCI/Handicap) which brings together the main organizations involved (Handicap International, CBM, Light for the World, etc.). This fosters more coordination and participation of OPDs with donors as well as with authorities.

In **Sudan**, The National Disability Council has a small budget for running of its Secretariat and relies on international donors (the Italian and Japanese development agencies in particular) for projects and capacity building activities.

In **Paraguay**, BtG has supported inclusive meetings gathering most of the actors. OPDs have appreciated the support provided by OHCHR for the joint development of the national plan for the rights of people with disabilities. As the technical knowledge of the High Commissioner was respected and very much taken into account, both by the participating government officials, as well as by the OPDs it created a good platform for participation.

2.3 Conclusion

As mentioned, the study is not an objective evaluation of participation processes and mechanisms, which would require many more resources. Its aims are to provide the basis for a collective understanding of the state of play in different countries and propose a framework to compare evolution of participation between countries over time.

The framework proposed reflects the fact that while ensuring meaningful participation is a state's human rights obligation and authorities frame its implementation, its realization will be the outcome of both government and the disability movement engagements and will depend of general governance context and the political economy of the sector.

In this context, there is no value judgement on the situation in different countries. The overall finding emerging from the study is that stakeholders' perception points to the fact that none of the countries have crossed a threshold that could be considered as ensuring participation, but all are getting closer.

Different issues identified which undermine participation and which are often compounded are:

- » There is little ground for consultation as there aren't many policies or programs aiming at inclusion of persons with disabilities due to lack of prioritization and resources allocation.
- » Consultation mechanisms may not have the required influence on government policies across sectors and on resource allocation.
- » There is too little support for OPDs for them to develop to critical level.
- » The disability movement does not yet have a real collective voice.
- » The legal and political context was not conducive for participation overall and cap possible civil society action as well as government staff initiatives.
- » There is clear lack of transparency of processes and collective access to data and information that is needed to allow engagement.
- » The lack of trust in public institutions and processes.
- » The lack of inclusion of most marginalized groups and women with disabilities and their issues.

On the other hand, one of the key learnings of the study is that each country has interesting practices and faces constraints, but all are somehow trying. By combining strong elements (which all have limitations and flaws) from these different countries one could build an enabling environment:

- » The overall level of policy development and investment, as well as financial support to OPDs of Ecuador.
- » The principles of election for OPD representatives in CONADIS from Paraguay.
- » The freedom and easiness of registration from Burkina Faso.
- » The direct relation of the national disability council with the President office in Sudan.
- » The technical capacities of CONADIS in Ecuador.

- » The strength and structuration of the movement in Ethiopia.
- » The engagement of Donors in support of OPDs in Burkina Faso and Ethiopia.
- » The initial support of Donors to national mechanisms in Sudan and BtG to stakeholders' coordination in Paraguay or Ecuador.
- » Using the framework developed for the study, we see that the five countries are somehow on the edge of participation but are in quite different situations.

We can distinguish different trends:

- **State driven:**

- » In **Ecuador**, higher level of government engagement has somehow asphyxiated collective OPDs engagement and lead to a disability movement that is co-opted rather than in a more balanced relationship.
- » In **Paraguay**, the process is also state driven with a significant impact of service providers who somehow create a screen undermining OPD leadership and development. The lack of capacity of OPDs creates a relation of extension.
- » In both cases, it is interesting to note that the national coordinating and consultation mechanisms (CONADIS), which have significant role and have more resources than their counterpart in African BtG countries, have somehow deflated the momentum or demand for a collective organization of the disability movement.

- **OPDs driven:**

- » By contrast, in **Ethiopia**, OPDs are fairly structured with a certain level of coordination. However, the political settlements and legal framework that prevailed the last decade directed their work rather towards service delivery and income generating. The State did not significantly invest in disability policy development and in really engaging with OPDs. The recent political change however can dramatically change the situation and could lead to a state of claim or basic participation.

- **Balanced:**

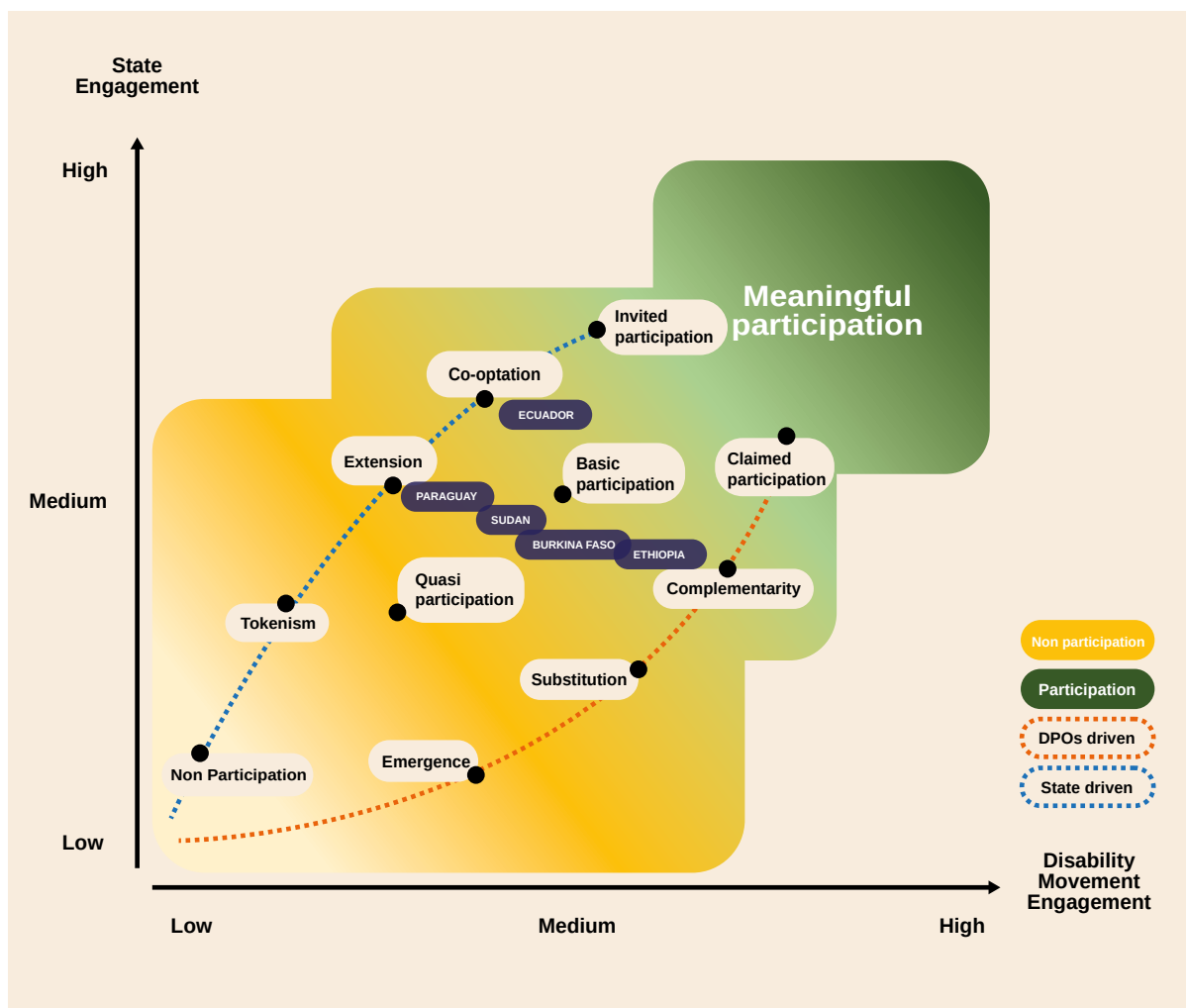
- » In **Sudan** and **Burkina Faso**, the level of government engagement is somehow matched by the OPDs engagement but remains in a state of quasi participation. The disability movement is either fragmented (Burkina Faso) or in the process of structuration (Sudan). The low level of policy development, resource allocation or level of policy prioritization so far might not bring the stakes to a threshold that would trigger meaningful debates. In both cases the political situation has a strong impact with an uncertain outcome in terms of evolution.

In all contexts, international cooperation actors are perceived positively and critical to ensure development and independence of the disability movement as well as

to facilitate the path towards meaningful participation. However, there is a clearer presence in Africa as compared to Latin America. In most contexts, there is a need for increased investment and support as well as extending genuine engagement with OPDs in major development programs.

International cooperation can indeed play a critical role in supporting capacity development of OPDs and government alike as well as facilitating dialogue between them.

Beyond needed financial and technical support, it can contribute to greater transparency and levelling the playing field by supporting production and dissemination of collectively needed data and information. It can also demonstrate by example the value of meaningful participation.



Part 3: Recommendations to international cooperation actors

The study recommendations focus specifically on the role of international cooperation (IC) actors in support of meaningful participation in CRPD implementation. Other resources such as the 2018 Australian DFAT paper “creating new business as usual”, develop broader recommendations on work of IC actors with OPDs.

The recommendations focus on 4 key areas:

- Transparency and access to required information
- Modeling by example
- Support to stakeholders
- Support to dialogue

3.1 Transparency

As mentioned, it is clear that the deficit of information, the lack of transparency of processes and the lack of access to data required to develop informed views on policy and programs issues are a key barrier to both OPDs’, but also to government coordination and engagement.

International cooperation can play a critical role and contribute to leveling the playing field between stakeholders in terms of access to information, which ultimately can facilitate cooperation and participation. This is true between OPDs and government but also between OPDs and other actors. It would definitely support most marginalized groups to access information that only few insiders may have and could facilitate the building of a common platform between OPDs for collective advocacy.

There is a critical need to support comprehensive and inclusive situation analysis which would contribute to build baseline and would facilitate monitoring. Support of IC to development of states and OPDs report to the CRPD committee are an interesting step. More systematic and sustainable work could be done in:

- Making the most of existing data sets (statistical and administrative data, geographic information systems) e.g financing production of census disability monograph, analysis of household income and expenditures surveys with attention to good quality disaggregation by disability, sex, age and location.
- CRPD compliant public budget analysis which would contribute to greater transparency, provide clarity on the level of investment and prioritization and could become a basis for engagement for OPDs in budget advocacy.

- Existing services mapping covering (re)habilitation, support services, education, inclusive support for victims of gender based violence, economic empowerment, social protection schemes and programs.
- Providing comprehensive information on ongoing and upcoming policy reform processes and major international cooperation projects and programs as well as an opportunities to engage. While this information may be available it is not necessarily framed in a way that facilitate for OPDs.
- Support in making the data available in accessible format.

3.2 Modeling by example

IC actors tend to face less local political constraint overall than local actors. They are in a position to set standards and example of meaningful participation. Combined with collective efforts of making data and information available, such efforts could contribute to greater trust between national stakeholders and could stimulate coordination between IC actors.

There are basics such as ensuring that staff has basic awareness about rights of persons with disabilities and inclusion requirement. If offices can only made accessible progressively, all consultations and public meetings are accessible and inclusive which may require provision of reasonable accommodation. It may imply higher cost which need to be factored in annual functioning budgets.

OPDs have limited resources and meaningful engagement in any process generate strong opportunity costs in terms of time and human resources. It is critical to support OPDs in identifying the key windows of opportunity for influence and provide them informant that will allow them to prioritize their engagement.

In order to facilitate OPDs engagement in different processes, annual consultation meetings could be organized by key IC actors (for instance coordinated meeting by EU delegation and members states for consultation and planning with OPDs. UN resident coordinator could do the same with UN agencies...) which would include:

- Overall presentation of key ongoing and upcoming programs (but does not replace program specific consultations).
- Key achievements of past year and key milestones for the next
Publication about who is doing what in which sector and what are the windows of opportunities for OPDs influence.
- Preliminary information and preparation with OPDs with focus on most marginalized groups.
- This could be complemented by regular smaller meetings during the year.

This would demonstrate value and importance of cross sectors and stakeholders' coordination. Efforts should be made to ensure meaningful participation of OPDs in major mainstream programs, in addition to what is one done for disability specific programs:

- It should include technical support to OPDs to help them to formulate their policy position to be effective counterpart.
- It would give credibility to OPDs both towards authorities and other CSOs and it would value OPDs leadership.
- It can contribute to create safe space for stakeholders to try and learn practice of 4.3.
- It can contribute to enhance or establish trust between stakeholders (Gvt-OPDs and OPDs-OPDs, OPDs-Service providers).
- Engagement of OPDs in major public policy / programs / budget support evaluation can be a great source of learning for OPDs and would help engage further and better in design of future programs and contribute to a culture of accountability.

3.3 Support to stakeholders and dialogue

As highlighted, meaningful participation is co-produced and requires not only political will but also institutional capacities on both sides. IC actors can have significant impact in that matter.

► Support to OPDs:

- Core funding at national and local level - while government's finance is important for OPDs functioning, the study shows that there are risks of lasting co-optation if OPDs do not access other sources of funding that guaranty their independence and autonomy. Moreover, in absence of such support they tend to focus on income generating activities which may divert limited human resources and capacities from core advocacy and representation mandate.
- Earmarking support in Call for Proposal - there is a need for acknowledgment that Civil society groups do not have equal opportunity to compete and access IC funds. Affirmative action is required and can take different forms to ensure that OPDs, especially the most marginalized groups are in position to apply successfully.
- Overall support should be provided both to support individual OPDs and to foster movement building:
 - » Develop policy analysis and advocacy capacity
 - » Collective gap analysis and advocacy platform building
 - » National and local coordination via umbrella cross disability organizations
 - » Greater connection between local and national level
 - » Support to inclusion of most marginalized groups and women with disabilities

► Support to government:

- In parallel to the support provided to OPDs it is essential to invest in capacity development of government staff and to embed training modules in pre-service and in-service training programs and institutions to tackle the issue of staff turnover which would enhance overall mainstreaming. Such training could be in part co-organize with OPDs.
- Supporting development of coordination and consultation mechanisms including in relation to decentralization.
- Setting up helpdesk with government disability focal point to ensure that staff in different ministries and local authorities benefit from the technical support they need to make their services inclusive. Such support could involves OPDs in response to certain request.

► Supporting and fostering dialogue:

- Supporting and valuing dialogue and involvement of OPDs in program and policy design, implementation and evaluation funded by IC.
- Supporting and valuing national and local coordination mechanism and supporting cross sector involvement.
- Supporting collective and evidenced based general and/or sectoral gap analysis and development of local and/or national disability inclusion action plan.

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Annex

Data collection framework

Data collection included desk review and interviews with key informants. It is to be noted that due to logistics and security constraints the following guidelines could not be used in all countries and therefore several elements have not been considered for the report as there was not enough information to compare between countries.

To build the framework for analysis of the country case studies required, to draw broader conclusions and formulate recommendations the study will:

- Carry out a desk review on the following themes
 - » OPDs participation, advocacy and capacity development, including IDA global survey
 - » Public participation in LMICs
 - » State CSO relationships
 - » Shrinking of civic space

- Carry out interviews with key informants from
 - » IDA and some of its members
 - » Some GLAD members

Considering the timeframe and resources of the study, neither the desk review nor interview can pretend to be exhaustive.

Country case studies

Background information

Prior to the country visit, consultants will carry out a desk review and interview with “key investors” and stakeholders involved in the considered country to build a country profile which will help during the visit. This will include:

- Elements about the general context, especially governance, to contextualize the quality of enabling environment provided to and actual engagement with OPDs
 - » Different governance related index (WGI, Transparency, etc.)
 - » Country case studies on civic space, civil society and public participation
 - » Existence of pro poor and inclusive development-oriented policies and budget allocation (UNPD HDR reports etc.)
 - » Main Donors’ country strategies (WB, EU, USAID, UN and other relevant agencies)

- Elements related to disability inclusion policies

- ▶ Review of state and OPDs reports to CRPD, CRPD concluding observations if existing, existing disability related project of major donors, IDA global survey outputs for countries and any relevant country report:
 - » Status of disability in government agenda
 - » Situation of persons with disabilities, in particular issues related to political participation and involvement in public affairs
 - » Policy efforts to achieve inclusion and implement CRPD (laws, programs, budget allocations, etc.)
 - » Paradigm framing disability related policies and programs
 - » Formal and informal consultation mechanisms and channels, including independent CRPD monitoring mechanisms and national coordination mechanisms
 - » Level of competition/support from service providers and INGOs

Country visits

The country visits will focus on interviews and meetings with OPDs, authorities and international development agencies as well as other possibly influential stakeholders.

- OPDs

Considering the study time limitation, attempt has been made to interview a set of OPDs that should give a sense of diversity of possible situation vis à vis participation processes and structures. The consultant will carry out interviews with:

- » The lead OPDs – most likely the national federation
- » Insiders – meaning a OPD who is likely in the position of power within the movement, such as the national blind union in many countries as well as the most active parent group
- » Likely outsiders – with at least one women with disabilities' group, and one self-advocacy groups of persons with deafblindness and/or indigenous people with disabilities, and/or persons with psychosocial disability
- » 2 local level OPDs
- » In addition, if the movement's political conditions allow, the consultant will seek to organize a focus group with all those stakeholders

- Other civil society organizations

In order to get a sense of OPDs role and political weight in civil society in general, the consultant will seek to interview:

- » one or two major (non OPDs) non for profit disability service providers if existing (it can be faith based or not) to get a different perspective information provided by OPDs and government on disability specific policies and processes

- » the lead NGOs umbrella and /or the main budget advocacy group to get a sense of the extent to which OPDs concerns are reflected in general civil society organizations
 - » The women's lead NGO and the indigenous group if relevant for the country, to get a sense of the level of mainstreaming of concerns of persons with disabilities in other identity-based groups processes, spaces and their advocacy
- Public authorities

While ensuring meaningful participation is primarily a duty of government, the study will focus on the experience of OPDs and therefore there will be limited inquiries with public authorities. The consultant will seek interviews with representatives of:

- » The disability focal point in government in general, and/or the focal point for the project
 - » The ministry of social affair (if not the focal point)
 - » The ministry of education
 - » At least one of other relevant ministry such as justice or local development
 - » A relevant parliamentary commission
 - » The National Human Rights Institution
 - » The municipality to which local OPDs belong
- Donors and international development agencies

The consultant will seek interviews with representative of at least:

- » The European union delegation
- » The project partner for the country (Spain, Italy, Austria)
- » One more relevant bilateral donor for in the country, ideally the biggest one (US, DFID, France, Germany, etc.)
- » A relevant INGOs working in disability, if any
- » UN resident coordinator office, or UNDP or UNICEF as most relevant

Through those interviews, the consultants will seek to gather perspectives of the different stakeholders on the several key issues.

1. Overall

The study is seeking to identify if governments are trying to ensure meaningful participation as well as the extent to which OPDs are actually influencing the public authorities' agenda setting, the decision made, the management of resources and the evaluation of programs and policies impacting persons with disabilities.

- a. How are the rules of engagement/participation set?
- b. How are the problems to be tackled by public authorities identified?

- c. How are the possible solutions to the identified problems considered?
- d. How are the final decisions about actions finally implemented? To which extent are there negotiations between OPDs and authorities?
- e. Who controls the resources used? To which extent are there negotiations between OPDs and authorities?
- f. How are the process, outputs, outcomes and impact of policies and programs evaluated?
- g. To which extent persons with disabilities at grass root level are aware and engaged in those participation processes?

Those questions may not be asked directly to stakeholders as they are more meta questions to which we should answer once we gather all stakeholders' views.

2. For government fulfilment of their obligations:

- a. To what extent existing regulations framing/impacting the functioning of NGO (legal status, legal requirements, foreign funding etc.) in general, and OPDs in particular, contribute or undermine meaningful participation?
- b. What are the different disability specific or relevant participation related mechanisms in place and their relevance for different stakeholders? This could be national disability council but also anti-poverty commission, human rights commission, the SDG national advisory committee etc. They will be perceived of different relevance by different stakeholders.
- c. What is the legal status of OPDs and of national disability coordination mechanisms?
- d. What are ministries and institutions involved? What is the level of staff (technical or political level and decision-making power) engaging with OPDs?
- e. What are the funding mechanisms and level of public funding for OPDs and disability service providers? It is also important to know if OPDs are receiving funding is it because they are themselves delivering services or is it to support their engagement as representative organisations. This influences to a great extent the politics in the movement.
- f. What type of support does the government provide to OPDs in general and to most marginalised groups in particular? Most marginalised groups refer to persons with disabilities from i) certain impairment groups (psychosocial, intellectual, deafblindness, etc.); ii) and/or affected by Intersectional issues and discrimination (women, elderly, children, poverty, remote location, ethnicity, religion, etc.) which varies from country to country.

- g. To what extent do engagement strategies and tactics of authorities support coalition building cohesion or exacerbate division and tension within the movement?
- h. To what extent do engagement strategies and tactics of authorities seek to co-opt OPDs leaders or do they seek true involvement of OPDs in policy making?
- i. What is the self-perception of quality of engagement with OPDs?

3. For OPDs engagement and representativeness:

- a. What is the level of engagement of OPDs in disability specific as well as other participation processes and mechanisms? Three levels (low, medium and high) in two categories invited and claimed can be distinguished. Invited is when OPDs have been invited to take part by a donor or government, claimed is when OPDs requested to be involved. High involvement does not distinguish between the invited or claimed as OPDs have developed in both cases very strong ownership of the mechanisms.
 - I. **Low:** (Invited space only) invited to take part but little involvement
 - II. **Medium invited:** invited to take part and actively involved
 - III. **Medium claimed:** OPDs requested to be involved (in mainstream mechanisms for instance) and are actively involved
 - IV. **High:** Invited and claimed. OPDs contribute to make the consultation space relevant and/or have demanded its creation and/or fought for its establishment or maintenance and are using it the maximum extent possible
- b. To what extent do OPDs cooperate or compete with each other in their relationship with authorities and donors? What is the level of cooperation or competition/division between OPDs? This can differ depending on issues, time, mechanisms. There can be “sides” (old OPDs against new ones, impairment specific against cross disability, OPDs against parents’ group, some disability groups against others, local against national). Were there any specific moments or issues (new law, CRPD ratification etc.) that have generated either the higher level of cooperation or competition/division?
- c. How confident are OPDs in their engagement with authorities and donors? To what extent do they frame agenda and participation space or are they mostly reactive to invitation and agenda set by others?
- d. What is the level of competition or support from service providers and INGOs in public participation space and access to resources?

- e. What are the key asks of OPDs to government and donors in different sectors (review also of parallel report, policy and advocacy papers, website, leaflets etc.) considering CRPD compliance, inclusiveness, equity – attention paid to gender equality and most marginalized groups? A mapping of the key asks can be done considering the following criteria: CRPD compliance, level of consensus among OPDs, inclusion of most marginalised groups, gender equality, technical and financial feasibility of the key demands. Those criteria are graded at 3 levels: high, medium and low.

	High	Medium	Low
CRPD Compliance	In line with CRPD	Not in line but moving towards compliance	Against CRPD (Denial of legal capacity or right to vote, forced treatment, segregated institutions...)
Level of consensus	Most OPDs support	A significant group of OPDs support	Few OPDs support, but impose it in the agenda
Most marginalised groups	Specifically aimed at inclusion of most marginalised (support to legal capacity, de institutionalisation, deafblind interpreters, CBR in remote areas etc.)	Not specifically targeting most marginalised but with attention to ensure that they can benefit from the program/policy	No attention
Gender equality	Specifically targeting gender equality and women empowerment	Attention to gender equality	No attention
Feasibility	Technically and financially feasible in the context within government capacity	Require external donor support but within government capacity in mid-term (5 years)	Would require extensive external support in finance technical assistance and duration

- f. What are OPDs engagement strategy and tactics towards public authorities and donors? Strategy would be either:
- I. Confrontation: disagreement and open opposition
 - II. Co-optation – disagreement but working with to try to convince them
 - III. Co-opted/extension – may be in disagreement but submissive or becoming an extension of government without critical approach
 - IV. Cooperation – in genuine agreement with the government
 - V. Complementarity/substitution: service delivery and advocacy mostly towards donors as little hope/trust that government will do anything
 - VI. In terms of tactics: Advising / Lobbying-Activism / Advocacy

g. How representative are OPDs of the diversity of overall population of persons with disabilities?

I. To what extent are all different groups of persons with disabilities:

- Formally organised
- Represented at national level

II. To what extent OPDs in general are perceived as legitimate to represent persons with disabilities in policy and decision-making processes by:

- Persons with disabilities themselves
- Government
- Donors

III. To what extent is the national OPD umbrella organisation perceived as legitimate to represent persons with disabilities in policy and decision-making processes by:

- Persons with disabilities themselves
- Single OPDs member of the umbrella
- Single OPDs not member of the umbrella
- Government
- Donors

IV. What is the actual and perceived mobilisation capacity of OPDs (organising well followed actions – demonstration, petition etc- reaching a critical mass of persons with disabilities)?

V. To which extent are OPDs actively engaging persons with disabilities:

- Providing them with adequate information in terms of quality, frequency and accessibility about on-going debates negotiation on programs, policies (websites, newsletter, social media, etc.)
- Consulting them on on-going debates, negotiation on programs, and policies
- Frequency of general assembly and election of boards of single OPDs and of the umbrella organisations
- Level of renewal in the board of the umbrella OPD in the last 10 years

h. What is the type of level of engagement of OPDs, if any, with other civil society groups, in particular:

I. Gender equality and women empowerment movement

II. Social justice movement (budget advocacy, etc.)

III. Democratisation movement

IV. Specific groups movement (indigenous, religious minority, LGBTIQ, etc.)?

4. For international stakeholders' contribution to meaningful participation:

- a. Do state/donors/INGOs' approaches support coalition building cohesion or exacerbate division and tension within the movement? This question, as many others in the framework, requires comparing perspective of the different stakeholders.
- b. To what extent do they foster dialogue between OPDs and authorities? This question needs to be answered by all. To donors: how do they try to foster dialogue between OPDs and authorities in the design, implementation and evaluation of your programs and funding (including budget support)? To OPDs and Government: to what extent donors' approach facilitates the dialogue with OPDs/Authorities?
- c. To what extent are they exemplary of what meaningful participation could be?
- d. To what extent do they reinforce inclusion of most marginalized?
- e. To what extent do they reinforce long term advocacy and representation capacity, or do they focus on donors' compliance capacities?
- f. What are the funding mechanisms and level of funding for OPDs and service providers?
- g. Self-perception of quality of engagement with OPDs



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