



# The Lost Link

## Localization of the UN Convention on the Rights of Persons with Disabilities

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On behalf of



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Title page photo: Meeting of the saving group VSLA Novilonlon in Togo. **Photo: CBM**

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## Contents

<b>Executive summary</b>	<b>6</b>
<b>1. Introduction</b>	<b>7</b>
<b>2. Methodology</b>	<b>10</b>
<b>2.1 Study 1: Scoping review of literature</b>	<b>10</b>
<b>2.2 Study 2: Scoping review of CRPD reports</b>	<b>11</b>
<b>2.3 Study 3: Semi-structured interviews</b>	<b>12</b>
<b>2.4 Data analysis</b>	<b>12</b>
<b>2.5 Ethical procedures</b>	<b>12</b>
<b>2.6 Limitations of the study</b>	<b>13</b>
<b>3. Key findings</b>	<b>14</b>
<b>3.1 Localization: the state of play</b>	<b>14</b>
<b>3.2 Obstacles to Localization</b>	<b>16</b>
3.2.1 Conceptualization problems	16
3.2.2 Context matters: Individual versus family and community rights	17
3.2.3 OPDs: from limited capacities to fragmentation	18
3.2.4 Politics as ‘the solution’ or ‘culprit’ for violations	22
3.2.5 Localization is costly	22
3.2.6. Awareness and capacity building on the CRPD	23
3.2.7. Siloed approach: Lack of disability inclusion in the mainstream	24

3.2.8	Fragmented data and information	25
3.2.9	Socio-economic, political, cultural and legal context	27
3.2.9.1	Political issues	27
3.2.9.2	Programmatic sphere	32
3.2.9.3	Legal terrain and justice	32
3.2.9.4	Poverty: where basic needs dominate	34
3.2.9.5	Cultural, attitudinal and historical dimensions	36
3.2.10	Representation issues	37
3.2.11	Intersectional terrains	39
3.2.12	Reporting and its limitations	41
<b>4.</b>	<b>Recommendations</b>	<b>43</b>
<b>5.</b>	<b>References</b>	<b>45</b>
<b>ANNEX 1.</b>	<b>ARTICLES ANALYZED IN SCOPING REVIEW OF ACADEMIC LITERATURE</b>	<b>48</b>
<b>ANNEX 2.</b>	<b>UN REPORTS ANALYZED IN SCOPING REVIEW</b>	<b>50</b>

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## Executive summary

The UN Convention on the Rights of Persons with Disabilities (CRPD) remains in place as the major disability rights instrument with a targeted focus on social development, grounded in the recognition that all persons with disabilities, with no exception, must enjoy all human rights and fundamental freedoms as every other person. However, the CRPD does not automatically confer realization of these rights for persons with disabilities, especially those at a local level, and indeed its ratification is but a start. Like any other international human rights convention, the CRPD needs to be entrenched in domestic policies and systems by national governments and other authorities to ensure a harmonized application that is then actively monitored. It means cultural and ideological change and socio-economic development. Even more importantly, its success hinges on its implementation and enforcement at the most local level, which is where marginalisation and deprivation may be most pronounced, especially in poor areas in the global South.

In response to this, recent years have seen increasing focus on what is fluidly termed ‘localization’ to highlight a process whereby international frameworks respond to and make a concrete difference in the daily lives of people in their homes and communities. Localization has also started to appear in international human rights law, demarcating a process of support for national, regional, and local governments, civil society and others in developing mechanisms and practices that effectively translate the CRPD into concrete practice and benefits on the ground. However, in practice, the implementation of the CRPD is far from simple, and the process of localization is frequently met by multiple and complex hurdles, most pronounced at the local level, where social, historical and other factors come into play. This meets a dearth of research exploring and documenting the process of implementation ‘on the ground’ in a range of contexts, meaning not only conceptual, but also policy and practice limitations. Overall, what we are left with is a scenario of deep fragmentation when it comes to the localization of the CRPD, meeting assumptions about the CRPD and its potential, too often left unquestioned.

This report presents the findings from a research project incorporating 3 studies to look at the extent to which the CRPD is being localized, and the factors and processes impacting the process of localization with a view to understanding the gaps and opportunity areas. The findings highlight a scenario of fragmentation and multiple barriers, becoming more pronounced in local rural areas in the global South. They demonstrate how “localization” still faces conceptual gaps, which means that we often do not know what we are actually talking about, and consequently how to set out to do it. This meets other barriers including: a focus on individual rights (as opposed to more communal ones); challenges faced by OPDs, their functionings and capacities; political and legal issues; representation concerns; a siloed approach where disability inclusion is marginalised in mainstream areas; lack of awareness of the CRPD; fragmented data; and socio-economic and cultural dimensions among others. Overall, while localization does happen on its own accord, the process is neither strategic nor harmonized, but is instead unsystematic and erratic, each local context left to its own devices. These barriers are accentuated as intersectional dimensions are factored in, including indigeneity, age, gender, race and ethnicity.

The study concludes with a number of general and specific recommendations, including: the need for active work on the conceptualization of ‘localization’ of the CRPD that establishes this as a systemic approach in its own right; a requirement to move towards the understanding and implementation of the localization of the CRPD as an ongoing process; responsiveness to context; the CRPD committee issuing a general comment on localization, to ensure that reporting procedures to the CRPD committee genuinely reflect local concerns; sensitization of UN country offices on the CRPD; generation of quality local data on disability; and support for countries to identify priority areas for localization and to develop a comprehensive strategic plan for localization. The recommendations go on to stress the need to ensure there are more individuals at a political directorate level who understand the CRPD and can effectively influence its implementation. Furthermore, they point to the need for a local

budget and funding to be made available; to review national policy frameworks and laws; and to work with local OPDs as genuine participants in the governance process. It is critically important

to ensure that OPDs are genuinely representative of all persons with disabilities, especially those in marginalised rural areas and not only a select privileged few.

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## 1. Introduction

It is estimated that persons with disabilities make up around 15% of the global population, the bulk of whom live in the global South, often in conditions of poverty and inequality (WHO and World Bank, 2011). They encounter a host of barriers in a range of areas including livelihoods, education, social protection, health care, and disaster management among others, and their rights are constantly violated, in some contexts more than others (Grech, 2015; Degener, 2019).

An important shift in response to this has come through the UN Convention on the Rights of Persons with Disabilities (CRPD). Opened for ratification in 2008, the CRPD sets out minimum standards for the rights of people with disabilities across a range of areas, for example health and rehabilitation, education, inclusion in the community, accessibility, the right to life, alongside advocacy on the equalization of rights of people with disabilities. To date, over 185 states have ratified the convention. Over the years that have passed since the World Report on Disability (WHO and World Bank, 2011) was published, there have been considerable developments also in global norms and standards relating to persons with disabilities. These included work by the Committee on the Rights of Persons with Disabilities tasked with monitoring the implementation of the CRPD, political commitments made through the 2030 Agenda for Sustainable Development (and reflected in the 17 Sustainable Development Goals (SDGs), and guidelines on the

inclusion of persons with disabilities in humanitarian action among others. There have also been many detailed reports documenting the situation of persons with disabilities from all parts of the UN system across all three pillars of the UN (human rights, peace and security, and development) launched through the UN Disability Inclusion Strategy (2019) with the set aim of providing the foundations for 'sustainable and transformative progress on disability inclusion'.

The CRPD, however, does not automatically translate into benefits for persons with disabilities. As with other international human rights conventions, national governments and central state authorities are responsible for entrenching the implementation of the CRPD into their domestic systems and context in order to meet their obligations. Indeed, domesticating the CRPD does not stop at a national policy level or merely because a State has ratified it. Instead, it hinges on the extent to which the CRPD is actually being implemented and enforced locally with dynamics in place to ensure that implementation and approaches are grounded, bottom-up, sensitive and responsive to the heterogeneous needs and complexities of very different contexts and lives. The CRPD should ultimately directly impact the lives of persons with disabilities in varying contexts who experience multiple forms of discrimination, especially those living in conditions of marginalisation and deprivation in the global South.

In practice, though, the situation is often quite different, and problems loom on the horizon, becoming accentuated as one moves from the international to the national and to the local. There have been a number of critiques of international human rights law and international human rights conventions, including that they are often State-centric, top-down, do not allow for local values and cultural differences and that they are ‘too technical-or abstract and aspirational, rather than practical and close to the people’ (Durmuş, 2020:36). Critics also highlight how the CRPD may be a one-size-fit-all policy, ratified with ease, but with little alertness to how local contexts encounter, react to, and perhaps even resist it. Critical work, has in fact been growing in recent years (see Soldatic and Grech, 2014, 2022; Harpur and Stein, 2022), alerting that there may be multiple barriers which impact the extent to which the CRPD is being implemented and to what degree of success (if at all), especially in contexts of extreme poverty and inequality in the global South. The barriers are multifaceted, including: poverty, lack of political commitment and gross human rights violations committed by States meant to protect them in the first place (see Grech, 2009; Najafi et al., 2021). Pons et al. (2021) stress how people with disabilities ‘remain largely neglected by the international laws, legal processes, and institutions that seek to redress those violations, including crimes against humanity (CAH)’. It is indeed no overstatement that while the wording of the CRPD may be excellent at a macro level, it is at a local level that concrete barriers to implementation are lived and become manifest. These include a host of structural, social, cultural, political, educational, economic and other obstacles, including whether the CRPD (or more basically, human rights) is even known or intelligible to local people with disabilities, their families and communities. Importantly, authors such as Pisani (2012) have stressed how conventions such as the CRPD are also ultimately bound to citizenship, with the implication that forced migrants and refugees for example are too often unable to claim their rights and are hence left exposed.

In response to this, there is a growing realization that integrated approaches to implementing the CRPD contribute to a more comprehensive implementation of it at a local level. The term ‘localization’ has in fact emerged and is increasingly

being used by UN bodies (e.g. UNDP) as well as bilateral organisations (e.g. USAID) to point to the need to make international frameworks a reality in the daily lives of people in their homes and communities, that ‘local spaces are ultimately the key site of delivery and development and, as such local actors are central to the success of sustainable development’ (SALGA cited in Global Taskforce of Local and Regional Governments, 2016:6). Localization (including capacity to enact the CRPD at national and sub-national levels) is a topic which is increasingly taken up by various stakeholders. It has recently started to feature in international human rights law, understood as a process to support national, regional, and local governments, civil society and service providers to develop mechanisms, partnerships, platforms and strategies to effectively translate the CRPD (intended as a human rights instrument with an explicit, social development dimension) into practice.

However, the implementation of the CRPD is far from straightforward. Documentation and evaluations of the process of implementation ‘on the ground’, so to speak, remain scarce. Faye Jacobsen (2022:2) in fact describes the state of research concerning localization itself as a ‘very young object of study’ where ‘empirical knowledge and understanding of human rights implementation at local level is still fragmented and scarce.’ This has serious policy, practice as well as discursive implications, not least the maintenance of an uncritical stance that can easily under-report problems and assume benefits of the CRPD. We urgently need to address the extent to which the CRPD is being implemented locally, how this is happening, and the factors and processes impacting the process of localization. This is because there has and continues to be uneven progress in the situation of persons with disabilities globally, including within countries. Evidence shows that despite an increased awareness of the CRPD, there is still a lack of scope for action and integrated approaches at local levels (see Lang et al., 2011). Even more critically, there is a dire lack of research on localization, and the conceptual terrain remains weak. More specifically, there is no single definition of ‘localization’ in the context of applying and implementing human rights frameworks, but instead there are a variety of concepts and conceptualizations, but few efforts to consolidate. The lack of a common understanding

contributes not only to weak conceptual understandings, but also practice limitations, not least coherence in objectives and strategies.

This report responds to these concerns, in particular the gaps in research and understandings of localization. It brings together the findings from a research project incorporating 3 studies to look at the extent to which the CRPD is being localized and the factors and processes impacting the process of localization with a view to understanding the gaps and opportunity areas.

This research project specifically set out to answer the following questions:

- How do local and national stakeholders understand and define localization in relation to the CRPD?
- What are the mechanisms through which the CRPD is being localized in different local contexts and communities?
- What are the roles of persons with disabilities and OPDs in the localization of the CRPD and what are their priorities?
- What are the power dynamics and issues emerging in the framing and localization of the CRPD at the Macro, Meso and Micro levels?
- What are the barriers and opportunity areas encountered by different stakeholders at different levels in localizing CRPD priority areas at local level?

The need for a study like this on the process of localization across multiple contexts is long overdue, not as a mere research project, but to ensure that the CRPD does have power and relevance at the local level, where it actually matters, that this localization is strategic and coherent across spaces, and importantly so that it can be genuinely transformative in the lives of persons with disabilities.

At the start of this study, we adopted a working definition of localization as: the means by which regional and international treaties and agreements are transferred and implemented by governments, private sectors, non-governmental organizations and individuals in their countries, companies, organizations, communities and home on a daily basis.

## 2. Methodology

The methodology employed in this study is grounded in a qualitative approach focused on foregrounding the views and perceptions of multiple stakeholders on the process of localization of the CRPD. The methodology actively drew on participatory-based methods to encourage dialogue between the research team and different stakeholders as well as the data. The research project involved 3 separate studies in the bid to generate diverse and extensive information on the conceptual and practical terrain of localization and to triangulate. These are discussed below. Components of the research project (notably interviews and the scoping review of the UN reports), focused on Jamaica, South Africa, Guatemala, the Philippines and Kenya. While the choice of these countries is arbitrary, it was deemed a reasonable and adequate choice because they are globally diverse; accommodate an emphasis on the global South; all countries have UN offices; all countries have ratified the CRPD; and all countries have submitted first reports to the CRPD committee.

### 2.1 Study 1: Scoping review of literature

A scoping review of academic literature (including grey literature) was undertaken to explore the extent and dynamic of engagement with localization in the literature. The objective was to explore the conceptual and discursive familiarity with the term in connection with the CRPD, since conceptual and theoretical terrains, including in the academic sector, ultimately influence practice too. A scoping review was deemed a suitable approach given that the localization of the CRPD has not been extensively researched (Arksey and O'Malley, 2005), while attending to the main aim of understanding and mapping evidence on the localization of the CRPD.

The search strategy, particularly with respect to the intervention terms, was refined in line with the recommendations of the University of Cape Town librarian and reference group and was tailored to each database. The following electronic

databases were searched: Scopus, Web of science, EBSCOhost, PUBMED, ProQuest PAIS INDEX, Google Scholar, UN. Additionally, a manual search was conducted to add publications that may have been missed from the original search and the selected databases. The following search terms were used with their truncated forms and Boolean logic to guide the search: localization of CRPD; contextualization of CRPD; regionalization of CRPD; domestication of CRPD; CRPD on the ground; CRPD in the field; CRPD.

A total of 2046 publications were located from the databases, exported to Mendeley and duplications were removed. This reduced the number to 1347. The cleaned publications were then exported to Rayyan.ai. and a screening of the titles and abstracts of the articles initiated to select the relevant articles. All relevant abstracts and full texts were double screened by two researchers and conflicts were resolved by these. The screening and selection process of the articles took 4 weeks. The publications selected after full text assessment totalled 22, and later brought down to 13 articles that connect with the implementation of the CRPD at local level. These were selected for analysis.

Data extracted from these publications covered the following domains: title of the research, location; year of publication; aim of the paper; study design; intervention; who defines the agenda of localization; the role of persons with disabilities and their families in localization of the CRPD; roles of organizations of persons with disabilities in localization of CRPD; challenges encountered by stakeholders in localization of the CRPD; outcomes and recommendations in localization of the CRPD. The inclusion criteria included:

- Papers published from 2008 (when the CRPD came into force) up to 2022.
- Grey literature
- Papers written in English.

Exclusion criteria included:

- Publications written before 2008
- Publications where localization or domestication are not linked to implementation of the CRPD.

## 2.2 Study 2: Scoping review of CRPD reports

A scoping review of CRPD reports was conducted to examine evidence of localization of the CRPD in reports existing in the United Nations reporting system. The online United Nations Human Rights Treaty Body Database was searched, as it ‘contains all public documents adopted or received by the human rights treaty bodies’<sup>1</sup>. An additional database was used to search for parallel and alternate reports, the WHO MiNDbank: More Inclusiveness Needed in Disability and Development<sup>2</sup>.

The search strategy focused on three different types of reports: 1) Periodic Reports from State parties; 2) Parallel/Shadow Reports from non-state actors such as national human rights institutions, organisations of persons with disabilities and other civil society organisations and 3) Concluding Observations Reports from the Committee on the Rights of Persons with Disabilities. The selection of these types of reports represents information from three different sources, thus providing varying perspectives on the situation regarding implementation of the CRPD in countries across the globe. This choice of report types also, to some extent, presents an opportunity for triangulation of data.

Periodic Reports from State parties refer to those reports that are submitted by each country that has ratified the CRPD, after their initial report. It is these documents that record progress in implementation of the Convention (often related to legislation and policies) post-ratification, according to the view of the State party. Parallel/Shadow Reports from non-state actors frequently focus on gaps in implementation of the CRPD according to the perspective of the rights-holders, and thus provide a counterbalance to the mostly positive reports

of national governments. Finally, the Concluding Observations Reports were included in this scoping review as they contain an external perspective which is developed by the Committee after consideration of all the reports and information related to one country from the State party and non-state actors.

The parameters for the search strategy were discussed with the research team members working on the larger study of the localization of the CRPD, as were the eligibility criteria for the reports and the data extraction, analysis and synthesis.

*Eligibility criteria:* In order to manage the large number of reports found through searches of the two databases, inclusion and exclusion criteria were applied. The inclusion criterion for the Periodic Reports from State parties was: reports labelled and categorised as periodic reports on the CRPD in the United Nations database. Initial reports, reports submitted to the Committee before 2011 and periodic reports that were not in English were excluded from this scoping review. With regards to the Parallel/Shadow Reports, the inclusion criteria were that reports from all non-state actors were included; reports had to be from Guatemala, Jamaica, Kenya, the Philippines and South Africa (in line with the focus of the larger study) and the reports needed to be in English or Spanish. All single-issue parallel/shadow reports were excluded (e.g. on corporal punishment of children). The Concluding Observations Reports from 2011 onwards were included in the study. The scoping review included only the ‘Positive Aspects’ section of the Concluding Observations reports as it is this section that reflects achievements in implementation (and possible localization) of the CRPD. Concluding Observations reports in languages other than English were excluded from the review.

*Data set:* Through the inclusion and exclusion criteria above, the final set of reports used in this scoping review is as follows: 28 Periodic Reports from State parties on all continents; 17 Parallel/Shadow reports from Guatemala, Jamaica, Kenya, the Philippines and South Africa; and 95 Concluding Observation reports from the Committee.

<sup>1</sup> [https://tbinternet.ohchr.org/\\_layouts/15/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4](https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=4)

<sup>2</sup> <https://extranet.who.int/mindbank/>

*Data extraction methods:* These included:

- a. **Periodic Reports:** A two-stage method was used to extract data. Initially a sample full-text analysis of three reports was conducted. This was used to identify key words and phrases related to or illustrating localization of the CRPD. This initial analysis was discussed with colleagues and modified accordingly. Subsequently, the words and phrases were used in a search of all the periodic reports. All related data from the periodic reports were extracted and entered into a table.
- b. **Parallel/Shadow Reports:** A full text analysis of each report was conducted to extract data on context, mechanisms, resources and outcomes of localization, in a similar framework to that suggested by Saul et al. (2013) for a rapid realist review. This data was entered into a separate table.
- c. **Concluding Observation Reports:** The same search words and phrases used for the Periodic Reports were used to extract data from the Concluding Observations reports.

### 2.3 Study 3: Semi-structured interviews

The third study was a qualitative study seeking to prioritise and articulate the views and perceptions of multiple stakeholders on the localization of the CRPD. Semi-structured interviews were conducted with key stakeholders in the 5 countries (Jamaica, South Africa, Guatemala, Philippines and Kenya) between August and September 2022.

The study involved purposive sampling. The participants included OPD members at different levels (micro-meso-macro), UN country representatives, as well as local, regional and state policy makers, and stakeholders at the community level who are centrally involved in community development. Participants were recruited from a sampling frame provided by key gatekeepers, including CBM. A total of 40 participants were selected (Jamaica 8; South Africa 8; Guatemala 7; Philippines 8; Kenya 9). The objective here was to have diverse views from different levels and phases of the localization process that would provide as

comprehensive a picture as possible. Participation was entirely voluntary. Interviews were conducted online using Zoom, Teams and Skype and lasted around an hour. Interviews were recorded with the permission of participants and then transcribed.

### 2.4 Data analysis

Thematic analysis (Braun and Clarke, 2006) was employed as the key approach across all studies. Thematic analysis was used to identify themes and patterns in the data that are relevant and pertinent to the research study objectives, in this case relating to localization. It provided an inductive approach to engaging with data as opposed to using predetermined criteria. The process involved the identification and coding of key themes that would then lay out the thematic areas on which the findings below are based.

For the scoping review of reports, initially, a qualitative analysis of the data from each type of report was conducted separately. Subsequently, the researcher used the overarching categories of 'context', 'resources', 'mechanisms' and 'outcomes' as used in realist reviews (Saul et al., 2013) to engage in a comparative analysis of the three types of reports, thus triangulating the data. Themes were developed for each category. The analysis of the data was discussed and modified with the help of the research team engaged in the larger study.

### 2.5 Ethical procedures

Formal ethical approval was obtained from the University of Cape Town (Ref. HREC REF 275/2022). All ethical procedures including informed consent, confidentiality, voluntary participation, and anonymity were rigorously followed in interviews while consistently highlighting the rights of all participants, including the right to withdraw from the study at any time. This research sought to adopt a decolonising approach. In this regard, the research team was aware of power dynamics and differentials, notably global North perspectives that assume expertise from a dominant position without consideration of local, especially indigenous knowledge and expertise. In this regard, we endeavoured to remain constantly vigilant of such dynamics.

## **2.6 Limitations of the study**

Like every other study, this research project has a number of limitations. The first is that the choice of countries is arbitrary, and findings cannot be generalized. We are aware that every context is different and so are the processes of localization. The scope of this research project, though, is not to generalize, but to provide a snapshot of localization that can inspire other research and possibly influence policy and practice. Another limitation is that all the studies favoured English speaking material and contexts. This is a major limitation that excludes multiple contexts and also continents, as well as perspectives from within these. This is especially the case when it comes to indigenous languages and perspectives where active efforts need to be in place for them to be heard and prioritized. This means that the findings in this report are positioned, contextualized, and need to be read with this in mind. Finally, this report and the research project more broadly are limited conceptually. Localization as a concept in regard to the CRPD is severely under-researched and the concept itself scarcely developed theoretically. This means that at various points, there may have been inconsistencies in its application and use.

### 3. Key findings

The following sections and subsections present the main findings from the 3 studies. A synthesis of these, highlights a complex scenario when it comes to the localization of the CRPD, including conceptual as well as practical concerns, all of which will be discussed below. It is important to note that all contexts are heterogeneous and also dynamic and these findings do not seek to simplify nor generalise the process of localization. In fact, as will be discussed below, localization is itself in a state of constant flux and motion, and importantly is complex and not quite understood. At the most basic level, the findings in this study lay out a landscape that is still in need of much more research not as a mere academic project, but one that can work closely with policy development and practice as a project of praxis to ensure the CRPD does have impact at the most local levels in sensitive, adaptive and responsive ways.

#### 3.1 Localization: the state of play

It was clear from the studies that while the process of localization may be affected by multiple factors and processes, and while there are active and intense barriers, the CRPD per se does have multiple positive aspects and which in turn legitimise further work into how to make these impacts stronger, more pertinent and responsive to the local level. The process of thinking about localization therefore appears to start with an active reflection on the CRPD itself within context and beyond the mere legal terrain (see Heyer, 2015).

The findings highlight how the CRPD continues to be important in bringing forward disability as an important issue at a social, political and also community level, not least in keeping policy conversations about disability inclusion alive. Participants in the interviews commented how it usefully shifts attention towards rights and away from charity, which remains a serious concern in multiple contexts, including in policy (see Afrianty, 2020). It also still serves as an effective tool for the awareness of the situations confronting persons with disabilities while pushing for a change in

narrative, including that persons with disabilities deserve rights. In this regard, it is therefore an effective source of public education too.

At a policy level, interviews highlight how the CRPD is an important tool for policy development, especially locally and regionally. Devolved policies then provide for an enabling framework for localization. In some cases, it also technically provides a possibility for local leaders to be held to account, even if evidence from this study suggests that this is not always the case. Even more broadly, the CRPD has and continues to serve as an instrumental means of putting disability and issues concerning persons with disabilities on the national and international radars (see also Kakoullis and Johnson, 2020). This is extremely important when disability too often remains marginalized, especially when compared to issues perceived as more important or urgent or that have greater policy and practice visibility (for example gender and childhood).

Importantly, the CRPD remains a critical source of emotional and psychological comfort as well as support for persons with disabilities, in a certain way, a source of solidarity. It also strengthens the call for persons with disabilities to lead on the process of inclusion and disability rights on their own terms. In this respect, they and their organisations have a central role in lobbying, challenging as well as working with government, and therefore operating on an active continuum of engagement. These quotes from the interviews highlight this range of perceived benefits:

*A really important international instrument that brings focus on the rights of persons with disability across the world (Participant, Kenya)*

*...and obviously, this convention provides the backbone and the thrust and the philosophy according to which things must happen in the country and it's not just guidance to state and also guidance to civil society and to business so we embrace it, we are very happy to have it (Participant, South Africa)*

*It is the awareness that it has brought about in regard to departure from charities to human rights approach to disability (Participant, Kenya)*

*We could rely on the importance of the UNCRPD on the ground and its usefulness as a policy development tool. It really provides a vision of an inclusive and rights-based society (Participant, Philippines)*

*...even if people with disabilities often do not feel the impact of the CRPD in their daily lives... they feel somehow supported on an emotional level...they feel that they are not forgotten in the international arena (Participant, Jamaica)*

However, despite these perceived positive dimensions, some patterns emerged that highlight a landscape fraught by localization problems, becoming more intense and complex at a local rural level in the global South. Evidence from the study, indeed, lays out a scenario of fissures and interruptions when it comes to the stated claims and ambitions of the CRPD as one moves from the transnational to the national and the local (see also Soldatic and Grech, 2014). A number of key points can be summarised as follow:

- Localization remains an unclear concept that means different things to different people: this is discussed below.
- Localization is happening on its own accord, but in a deeply fragmented, unstrategic and possibly unsustainable way
- An urban bias envelopes localization, that is in more impoverished and isolated rural areas, there are less benefits that can be directly attributed to the CRPD:

*If we look at the population, its majority is in departments and I would dare say that that the largest percentage really do not know of the existence of the CRPD, including laws pertinent to their*

*rights...and therefore not many benefits we can speak of (Participant, Guatemala)*

- The process of localization bypasses or remains ill-equipped to deal with indigeneity and related intersectional areas (see below)
- Empirical knowledge on localization is still fragmented and scarce
- The implementation of the CRPD may be top-down and too state-centric and dependent
- Cultural and contextual differences and heterogeneities may often be relegated to the back in the bid to simplify and generalise the process of localization.
- The CRPD may be seen as too technical, at times abstract and also very ambitious and isolated from real needs of real people on the ground in rural areas.
- The impact of localization efforts is very differently perceived by different stakeholders in different geopolitical spaces: for example OPDs operating at an urban level in positions of power, may see it as hugely successful whilst those operating at a more regional and local level, do not see the CRPD as particularly transformative, especially when it does not yield material benefits for poor persons with disabilities in rural areas in the global South.
- National Disability laws based on the CRPD are not seen as enforceable by many, and where formal structures are in place, they appear to often not be working
- The CRPD is understood to play a role in social transformation, but there is no strategic focus, collective understanding or guidelines as to how this can happen, who is going to lead the process and so on.

- The emphasis on OPDs, paradoxically places attention on persons with disabilities themselves as responsible for their own well-being: while the critical role of OPDs cannot be emphasised enough, it can also run the risk of deflecting attention away from what societies, governments and mainstream institutions need to concretely do to account for genuine transformative change.
- Related to the above, any benefits may be more readily attributed to the involvement of Civil Society Organizations (CSOs) as opposed to more local government led-initiatives. More specifically, impact is more directly related to if and how CSOs have been able to use the CRPD.

What emerged solidly across the 3 studies is a scenario of complex and multi-dimensional obstacles that impact if and how localization can happen in practice. We discuss these obstacles below. It is important to note that these are not mutually exclusive, but often operate in unison with more intensity in some contexts than others.

### 3.2 Obstacles to Localization

#### 3.2.1 Conceptualization problems

The first obstacle that deserves attention and that cross-cut all 3 studies was a lack of clarity as to what localization actually means in regard to the CRPD. There is weak understanding of what the process of localization actually involves and a corresponding scarcity of evaluation of effectiveness of any approaches that claim to do so. This situation is accentuated by a profound scarcity in research and theoretical developments on the subject, and which would help frame localization conceptually (Faye Jacobsen, 2022). Findings from the scoping review of academic literature demonstrates that while there is a fluid reference to a process of local implementation, there is still a dearth of material that harmonises localization as strategy and practice which is done sensitively and responsively. This is a serious absence because without conceptualization, it remains unclear what we are actually talking about, what we are meant to do, and how to set out to achieve this in practice.

The interviews highlight how some people think that national ratification is localization in action, while others understand it either as process or impact in communities at local level. For others it is about the implementation of a national policy, while for others yet, it implies the need to contextualize and provide feedback from the grassroots to a national and even international level. In some instances, it may also be seen in terms of local policies and as a tool to push local government to consider the rights outlined in the CRPD. Indeed, lack of coherent understanding is what typifies the scenario. These quotes present the diversity of views:

*Honestly, I do not know what you mean with localization. Does it mean you have results locally, or is it more a process?...of things you need to do that you can implement it in a village for example... (Participant, Jamaica)*

*How I understand localization is that it is considering the capacities and culture of a community. (Participant, Philippines)*

*Localisation is bringing the CRPD to our national and local levels (Participant, Kenya)*

Interviews highlighted a situation where localization appears to simplistically imply or serve as a proxy for the implementation of national laws and policies or the mere ratification of the CRPD by a country:

*So localization to us is like domesticating what is international to fit into the national context (Participant Kenya)*

*It means that the CRPD is being put into laws in Jamaica that we then have to observe and in force. (Participant, Jamaica)*

There appears to be an inherent (and erroneous) assumption that if laws and policies are merely put into place, then the CRPD will have automatic relevance at a local level and its terms actually fulfilled by default, even if there may be some understanding that this is far from enough.

In this regard, while critical literature is growing (see for example Rivas Velarde et al., 2018), overall there is still scarce reflection on the factors and processes, including barriers at the local level that not only

impact whether the CRPD can achieve anything at all, but also whether it has any currency to local people in dispersed rural areas in the global South for example (see Grech, 2009, 2015 for more on this). Indeed, the process of localization is politically loaded, but debates on localization paradoxically ignore the politics that frame and determine its boundaries and reach. These issues will be discussed below. As Dolmaya (2018) stresses in the opening line to her chapter, ‘To discuss the politics of localization, we first need to define both politics and localization’.

In debating the complexity of conceptualisation, a number of dynamics emerge. In some instances, localization may be seen simply as an approach, even a restatement of existing conventions, and hence there is scarce to no reflection on what makes the localization of the CRPD particular, with its own specific baggage of complexities and nuances. The following quote highlights this tendency for simplification:

*Since it ratified, and based on the constitution, any treaties of international conventions we agree to become part of the law of the land. So basically it also became part of the law of the Philippines. When it is part, then it is part, then it is included in our domestic legislation (Participant, Philippines)*

It was also interesting to note that in interviews there was a propensity to speak about barriers as a proxy for an implementation process that reflects on ground problems. But within the conceptualization problems and differences, one pattern was particularly pronounced. This involved the tendency to see localization as a linear, somehow organised one-way process from top to bottom, to somehow fit the CRPD nationally, when in practice it is a complex, diverse and dynamic process often determined by a range of connected and even conflicting factors.

### 3.2.2 Context matters: Individual versus family and community rights

Another emerging theme fluidly related to the issue of conceptualization is the understanding of rights as individual rights and the role of the CRPD in securing these individual rights.

*We have to be able to determine our rights. We ourselves should know how to claim our rights as individual persons with disabilities. (Participant, Philippines)*

In the process of localization, there is therefore possible marginalisation of communal rights, especially in the global South, as well as how families and communities impact the possibilities of granting these rights to an individual in practice, whether individuals even want them, and/or would opt for protection of their communities instead. There is also limited understanding of the CRPD through a communal rights perspective, and how local dynamics and processes (community development) need to be influenced in contexts and cultures where rights are collectively framed and sought (Grech, 2015). As Harpur and Stein (2022:92) explain, the CRPD text focuses on individual living rights, but this global North individual rights focus too often clashes with the global South’s ‘communal and family focus’. These authors go on to focus on indigenous cultures to suggest how frequently rights are viewed as holistic, relational, and collective.

To be clear, while articles in the CRPD do make provisions for communities, for example non-discrimination and changes in attitudes (Article 5), the way it is interpreted often does not account for the stronghold of these cultural and communal factors and how any process of localization, and also possibilities of achievement of rights needs to engage with and be filtered through these. There is no localization without the communities it is localized in. This excerpt articulates some key points in the context of indigenous populations:

*Leadership and involvement in advocacy were strongly linked with gaining an awareness of disability rights, including rights to health. Indigenous peoples’ leadership was also linked with positive health policy responses... Indigenous senior policy makers believed that there was a lack of advocacy and local engagement arising from a history of having programmes and policies imposed. They believed that community leadership must emerge from within the community if it is to be sustainable and legitimate (Rivas Velarde et al., 2018)*

What emerges clearly is a perpetuation of the fact that, just like the CRPD itself, much of the discourse on human rights is premised on global North assumptions that are far from universal round the four corners of the globe (Soldatic and Grech, 2022). This may include, for example, the assumption that OPDs are in place and/or that advocacy and organizing politically is a socially and culturally acceptable practice, or that there are some or other systems of social protection that can be claimed by these poorest local people. In the process, it denies the nuances of contexts and communities on the ground, not least the pervasive poverty, and which in turn forces a serious reframing of the assumptions the CRPD takes off from. Meyers (2018) articulates this succinctly:

*...the CRPD contains a “civil society mandate” founded upon Western assumptions of how disabled persons organisations (DPOs) should act and the disability consciousness and political advocacy that persons with disabilities should hold...Through its article on civil society, the CRPD has globalised the expectation that both disabled individuals and their DPOs will be oriented towards rights advocacy. Developing DPOs and a disability consciousness according to the Western experience is therefore a central mission of the global disability movement that is promoting the CRPD. Several comparative studies of disability that take local context seriously point to another major difference in context – dire poverty.*

This participant in Guatemala further elucidates these points:

*Of course, there are many and very evident disparities between how persons with disabilities live in developed countries compared to poor ones, it is well evident. Also, because in these developed States, there is a generalized basic standard of living that has been achieved over the past 50 years, but which hasn't in poor countries...and so persons with disabilities have many opportunities so that they can exercise their rights, while those*

*in poor countries say that so much is lacking in their lives (Participant, Guatemala)*

### 3.2.3 OPDs: from limited capacities to fragmentation

The critical participation and assumed role of persons with disabilities and their respective organisations cross-cuts the text in the CRPD and also the bulk of the literature scoped in this study, to the extent that such discourse is expected, almost as a point of legitimacy. The role of such OPDs on paper appears to be broad: to engage in consultations with powerful stakeholders on policy and practice; to monitor the implementation of policies; to advocate; strengthen leadership; push forward representation, especially of marginalized segments of the population with disabilities; and to influence other tiers of governance.

An important mechanism for localising the CRPD is the inclusion of organisations of persons with disabilities in measures taken to implement and monitor the Convention. The CRPD Committee notes national government engagement with OPDs in the design of legislation, the coordination of implementation of the CRPD and also in the reporting process to the United Nations in a number of countries. Although national engagement with OPDs is not necessarily a mechanism for localization of the Convention, several countries describe the involvement of OPDs also in the development of guidelines and policies which may have a direct impact on localization of the CRPD. The third periodic report from Nicaragua, for example, explains how:

*...two guides on inclusive risk management have been prepared, namely, the Guide to the Participation of Persons with Disabilities in Departmental, Municipal and Community Response Plans and the Guide to Preparing Family Emergency Response Plans (with an Inclusive Approach). These guides were prepared with the active participation of organizations of persons with disabilities (CRPD/C/NIC/3, 2020:11)*

In Malawi, persons with disabilities participate in local level Civil Protection Committees to coordinate

and implement disaster risk management interventions (CRPD/C/MWI/1-2, 2019), while in Lithuania, OPD representatives work together with municipal officials to assess accessibility of polling facilities (Republic of Lithuania, 2021).

Involvement of OPDs and persons with disabilities in the localization of the CRPD also relates to political participation and empowerment. For example, United Disabled Persons of Kenya reported that 44 out of 47 counties of Kenya had at least one person with a disability seated in the county assembly, as at 2015 (ICO KEN 20210, 2015). Similarly, the Nicaraguan government reported that there were 22 mayors or deputy mayors at local government and municipal level who had a disability and 226 persons with a disability who were town councillors in the country in 2019 (CRPD/C/NIC/3, 2020). As the result of a larger project in Moldova supported by UN Women, eight women with disabilities participated in the 2019 local elections as candidates, six of whom were elected as local councillors (Republic of Moldova, 2020).

While the need for such participation and for persons with disabilities to own and define the rights agenda is indisputable, it does not mean that this process is straightforward, unproblematic or even possible in some contexts. However, one corresponding finding is the scarcity of research and documentation of the barriers to participation in practice. Nevertheless, a small number of academic articles reviewed provide a glimpse. For example, Rivas Velarde et al. (2018) highlight a continued trend of continued imposition of policies on indigenous people and also how programs showcased by northern INGOs for publication as well as best practices do not always reflect realities on the ground, including concrete barriers to participation by OPDs in debates and practices, not least on account of poverty and inequality. Findings from the interviews, in particular, highlight how what is actually faced is a situation of excessively high and unrealistic expectations of what these OPDs can achieve in practice, especially those in poor rural areas in the global South:

*We have some organisations that may have a better structure, a stronger voice, but level of participation is limited. In reality, no, the*

*country, the State does not have mechanisms articulated at a national level, at a local level, that would permit the participatiattend the demands, and protect persons with disabilities in relation to the legal framework...even if they (State) try to integrate at any moment...and conclude that persons with disabilities should participate in the debate, this participation, many times, is not substantial. They (persons with disabilities) are in the space, but the participation is not one with proposals, with a dialogue*  
**(Participant, Guatemala)**

The studies highlight a plethora of problems, all of which seriously challenge the claims as to the potential of OPDs in leading on the localization process itself. These problems are internal and external to these OPDs:

- OPDs frequently do not understand the process of localization: while international efforts are in place to educate OPD leaders on the CRPD and the SDGs (e.g. the Bridge CRPD/SDG Training Initiative by IDA and IDDC) and this is commendable, there is much more that needs to be done to reach all stakeholders, especially those at the most local and rural level.
- OPDs often cannot articulate their concerns in a focused way to the right stakeholders, also because they do not quite understand the political system or how to communicate with politicians:
  - ...disabled people need to bring out a clear message. Politicians do not know about their situation, but their (disabled peoples) representatives often do not articulate what they actually want. You need to have a focused message to achieve change, not just complaints **(Participant, Jamaica)**
- OPDs are overshadowed and overpowered by service providers, and the voices of the latter are often stronger:

*There is also a very vertical relationship between service providers and persons with disabilities, and so service providers*

*here, still take priority when they speak... they are the ones that go to government to ask for things, that go to congress to speak to ministers, while we people with disabilities continue to be seen as objects of charity (Participant, Guatemala)*

- OPDs, especially those from poorer rural areas lack social and financial capital, which would help with providing gateways to powerful people. Many members of these OPDs live in poverty themselves:

*What I am really trying to push for now is the organizing of persons with disabilities in our municipality and in the province so that we can truly have a voice, but it is often difficult to move or do anything because there is no financial support. I have to dip into my own pockets. Thus, I sometimes feel so disheartened especially when I request for support and the only word I get is that there are no funds available. (Participant, Philippines)*

- Even basic structures like government buildings as well as transportation are frequently inaccessible which limits what OPDs can actually do and who they speak to, while adding costs (direct and indirect), and serving as a reminder that accessibility and openness have a long way to go. This participant in Guatemala explains the ordeal of trying to enter a municipal building:

*...for example if I want to go to the municipal offices, there are no ramps. I wouldn't be able to get in because it is full of stairs and even the borders of the park, for example, is inaccessible to me, and it is there we can begin to see that...they haven't done anything (Participant, Guatemala)*

- Fragmentation and internal problems: evidence from the studies highlight a scenario of fragmentation between and also within OPDs. Overall, this challenges discourse of joint and concerted action (see Love et al., 2019) or that OPDs necessarily act in benefit of those who are most marginalised or even represent their concerns. A number of dynamics emerged, in some places more than others:

- Fragmentation in the disability sector means that governments do not always know who represents the OPDs and who they are meant to work with.
- Less powerful voices are frequently not heard or ignored, for example persons with disabilities in poor rural areas. Many OPDs hardly stray off the beaten track. This means that the interests and needs of those in isolated areas are not known and not articulated by privileged OPDs sitting on important national and international fora:

*Yes they probably make an impact, but where are they making this impact? Where is the funding? They are not making the impact. I mean, I am involved in X (rural location)...rural area, there are 240-something blind people and I go there to help them. Why? Because organisations are not reaching out to them. (Participant, South Africa)*

- Infighting and lack of cooperation: Some OPDs want to do their own thing and 'shine' on their own and not collectively and may even be in competition with each other, particularly with regards to sourcing funding for operational requirements. This minimizes impact that can only be achieved by working together. This quote from a South African participant lays out a rather problematic scenario:

*Why do they have to start their own organisation, why every corner you go somewhere, someone is starting a new organisation. Not on. You need to hold hands to have a bigger impact. And they are not willing to hold hands...there is a lot of unnecessary sibling rivalry if you want to call it that, between organisations with disabilities because each one wants to be better than the next. Each one wants to say they know more, each one wants to be the full representative of persons with disabilities. Which why, what's the point there? Because then you are fighting for power, you are fighting for recognition and what happens to the persons with disabilities then?...I know that people*

*are doing something in their corners but it is not enough and we are not making a positive impact (Participant, South Africa)*

- The goals of some OPDs may not necessarily be aligned with those of persons with disabilities in poor rural areas, and may indeed not fully represent the interests of the latter:

*Organisations of Persons with Disabilities, I don't think they are doing justice...because they are after money. They are getting funding from whoever, Lotto and government and private funders and overseas funders and whoever. And then what happens is they want increases in their salaries and whatever and they want to go and have lavish dinners in hotels and things like that, but then they want to charge for resources...It is an NGO...you need to treat it as that. And if you go into that line, you can't expect the salary of 30 or 40 thousand Rand. Because that is not going to happen or it shouldn't be happening. So I believe that a lot of funds are being misused. (Participant, South Africa)*

- Lack of skills and capacity to design and implement programs, as well as scarce technical knowledge, for example in fundraising or legal frameworks.
- OPDs may be overstretched and require input from mainstream stakeholders because they cannot cope with the demand, but this support is not forthcoming as the mainstream may be unaware or disassociated from disability issues, or when it does, it is not of high enough quality (see below).
- OPDs need international funding to monitor and to write shadow reports: shadow reports from Kenya and the Philippines acknowledge how persons with disabilities have benefitted from such international funding. United Disabled Persons of Kenya, an organisation of persons with disabilities (OPD), describes the results of international co-operation in terms of local impact: 'increased participation

of persons with disabilities in community activities, leadership, education and employment.' (ICO KEN 20210, 2015:40). However, this means that they are dependent on international donors, but this funding is often scarce or only goes to ones that are well positioned with structures in place to receive and manage funds. These are rarely OPDs in impoverished rural areas.

- Related to the above, the success of an organisation is contingent on whether one is located in an urban or rural area.
- The number of organisations that make it to a national delegation depend on the resources of the country, which means that the more impoverished ones are too often absent or under-represented.
- Non-state actors in the shadow reports also describe situations in which OPDs and other civil society organisations provide services with funds raised through charitable means which ought to be provided by the State, which can have a detrimental effect on the State fulfilling their duties. Such a situation is described in a shadow report from Guatemala:

*In most cases for a treatment or rehabilitation process persons with disabilities have to travel to the city where public services for this care are scarce...In the departmental capitals and in some municipalities there are centers of private entities that for many decades have raised funds through raffles, telethons and others, which has reduced the responsibility of the State. (CSS GTM 23394, 2015: 26)*

### 3.2.4 Politics as 'the solution' or 'culprit' for violations

Localization of the CRPD is complex and involves multiple and interacting levels, including where the obstacles are and the multi-dimensionality of possible interventions. However, findings from the study highlight how there appears to be an almost exclusive focus on government, politics and political processes as both the perpetrator of violations and where most if not all solutions to these actively lie:

*From what I know, if politicians and government officials from the national (government) go to the local, local officials will listen to them. I think there is a need for outsiders from the national government to tell the local government what to do*  
**(Participant, Philippines)**

*I think the private sector and even NGOs look at the government to start leading on it (the implementation of the CRPD). So where the government is silent, you know, then it sort of creates challenges because then the movement may not happen...*  
**(Participant, Jamaica)**

*The government is seen as the devil...and a saviour at the same time...things are much more complex than this*  
**(Participant, Guatemala)**

Overall, the disproportionate focus on government is opposed to seeing society as a complex conglomerate of many factors including social, community, economic, cultural, religious and ideological, and geopolitical dimensions, among others, and which is where effective change needs to happen, involving a combination of efforts, often working in unison. In this regard, in much discourse on localization, there is a simplification of the pathways of implementation limited to the political and the legal. In turn, it reinforces the lack of attention on other dimensions and areas that need understanding and active engagement in, including social processes, how communities encounter and may also resist the implementation of the CRPD, how economic factors may condition political allegiance and so on. While corruption, misuse of funds and bad governance are indeed major factors, an exclusive focus on these, simplifies the whole picture too much. For example, it may deflect attention away from how mainstream organisations may be a source of disablism or how they can cooperate with the disability sector to provide critical support and alliances.

Communities also take care of themselves. Devolution of power does not only take place from national government to regional and local government, but also to non-state actors. An interesting example from New Zealand is reported regarding interventions to improve opportunities

and wellbeing with regards to health, education, housing, employment, standards of living and cultural identity of whānau ('Extended family, family group, a familiar term of address to a number of people – the primary economic unit of traditional Māori society.'), including persons with disabilities:

*Whānau Ora takes a strengths-based approach to empower whānau and to create intergenerational improvements in wellbeing. Whānau Ora is delivered through a 'devolved commissioning model'. This means that non-governmental agencies are contracted by Government to deliver a set of wellbeing outcomes.*  
**(CRPD/C/NZL/2-3, 2019:7)**

### 3.2.5 Localization is costly

In much of the discourse and orientation on OPDs taking charge, and the assumptions made about the power and reach of the CRPD itself, there is also a corresponding assumption that the CRPD is implementable everywhere. However, one core point that is not adequately addressed is that this process of localization is far from costless. On the contrary, localization, as evidenced in this study, is a very costly exercise, in most contexts prohibitively so. Localization is indeed not a philanthropic action left up to people or that governments can easily address, but requires core changes, including structural ones, for example converting infrastructure and buildings that have been inaccessible for decades if not centuries. It means working actively to change attitudes and counter ableist tendencies in government departments and societies, to even begin to legitimise these investments by making them more socially acceptable and palatable. It means genuinely empowering people and organisations to be able to seek redress and claim their rights, courts and justice systems that are disability-aware and educated, and importantly investments in the poorest and most rural areas where poverty is deeply structural and historical. This is even more serious in indigenous areas where racism meets political isolation and economic deprivation.

*...in the city it is a bit more accessible...even if there is still much to do... you can at least get into a place and be a bit independent...but here, in my village, I feel it is more difficult*

*for me...to get out to a place here, you cannot do it alone, to be a bit more independent....as an indigenous person, things are harder...we are like totally invisible (Participant, Guatemala)*

### 3.2.6. Awareness and capacity building on the CRPD

Two of the main mechanisms through which the CRPD is meant to be localized, and which emerge in the articles scoped, appear to be awareness-raising and capacity building, including on the assumed possibilities offered by the CRPD and also on disability to key stakeholders. These include policy makers, development actors, OPDs, professionals, local councillors and municipal authorities, and also communities among others. Particular attention is devoted to capacity building of OPDs which is intended to equip them to lead on the process. Lord and Stein (2008:467) capture this process: 'facilitating the expressive value of the CRPD through education and empowerment at the individual and community level, strengthening the organizational and advocacy capacity of DPOs'. The importance of capacity building is indeed emphasized and broad:

*...actions to build the capacities of disabled people's organizations (DPOs) and networking of these associations... raising awareness and training local development actors on the issue of disability (Boucher et al., 2015)  
...need to sensitize people, including policymakers, on disability issues so that the rights of persons with disabilities will be recognized and accepted. (Opoku et al., 2016)*

*Ways must be found to include indigenous peoples with disabilities fully in communities, building upon their capacity and literacy about human rights, particularly about the CRPD (Rivas Velarde et al., 2018)*

One critical factor here is a strong focus on capacity building as a prerequisite for local acceptance and implementation of the CRPD. However, what emerges clearly is that this emphasis is borne of an often-dramatic lack of knowledge on disability rights as well as the CRPD itself, including by UN agencies, and becoming more intense at a local level:

*I do not think that people in local communities understand CRPD, what it means and what is its aim (Participant, South Africa)*

Socio-economic, cultural and other barriers in communities on the ground mean that national laws, not to speak of international frameworks, are often neither known nor necessarily seen as relevant in local rural contexts (see Grech, 2015), including by those responsible for implementation such as local politicians. More specifically, raising awareness does not automatically mean that anything will be done. These barriers are discussed in the next section. The following quotes from the literature and the interviews highlight the situation in practice:

*Despite the ratification of the CRPD by the Uganda Government and the awareness creation on the CRPD to leaders of district Local Governments, National Council for Disability while fulfilling its mandate of monitoring implementation of programs by Government and other implementers at all levels, discovered the remaining 110 districts had not domesticated the CRPD. This was attributed to limited information on the CRPD and knowledge of how to domesticate the Convention, coupled with lack of understanding on the benefits of domesticating the Convention at district level (Guzu, 2015)*

*A total of 21 participants did not know the UNCRPD, its contents, and any other disability policy documents in Namibia. Persons with disabilities do not understand that the UNCRPD is a tool that empowers them to advance their rights or hold anyone who violates their rights to account. (Chibaya et al., 2021)*

*You need to have a minimum of education for the CRPD to be relevant and this is the problem, that people do not have this minimum of education and so if you go to X (rural area), for them (rural people), they couldn't care less whether you speak about the CRPD or not (Participant, Guatemala)*

This lack of awareness, as evidenced in the interviews, becomes even more pronounced in indigenous rural areas, where geographical,

linguistic, economic and cultural factors combine to produce a situation of critical isolation from a CRPD that is ontologically, materially and even linguistically isolated. This also includes the modes in which it is communicated, which may not always be relevant to local ways of learning:

*...as women with a disability, indigenous...it is a challenge, it is survival...many of us have not had the opportunity to study, we have no knowledge of anything...we cannot just turn up with a woman with a disability, from a rural area and speak to her about the CRPD, she will not even know what you are talking about...and the way of learning, the way of explaining it to this person, is going to be different, there will always be different ways of learning and understanding what is being told to us...and another thing is the language...it is well complicated all of this*  
**(Participant, Guatemala)**

Shadow reports from the five countries indicated that there is a need to increase awareness of the rights of persons with disabilities amongst the general population from community-level to national level. Non-state actors from Jamaica and Kenya, specifically, recommend that the State should implement interventions to raise awareness of the CRPD, while the South African Disability Alliance suggests that a public-private partnership could undertake such interventions. Non-state actors from the various countries also suggest that organisations of and for persons with disabilities should be involved in the awareness raising activities. Despite these consistent calls for more awareness and capacity building, the review, though, reveals that there are neither clear nor consistent guidelines on how to go about doing this, nor informed and contextually sensitive strategies. Indeed, it would be safe to say that there is much talk, but little to no corresponding informed action. There is a constant mention of the need to involve persons with disabilities in this process, but limited evidence of any sustained sensitization campaigns and capacity building driven by local OPDs themselves.

### 3.2.7. Siloed approach: Lack of disability inclusion in the mainstream

One theme that emerges with substantial force in the studies is the excessive and almost sole focus

on disability-specific interventions working within disability frameworks such as the CRPD. In the process, it appears to bypass the same mainstream which is in fact the space that needs to be influenced and impacted, not least because that is where effective alliances need to be built to ensure the CRPD can indeed be localized and to deliver (see Skarstad and Stein, 2017 for more on this). It is also where disabling and exclusionary practices may be located and hence need to be tackled. Evidence from the studies, in fact demonstrate a scenario whereby mainstream stakeholders, for example development, humanitarian and other organisations as well as those working across other thematic issues (e.g. gender, childhood or indigeneity) are not actively involved in discussions or even reporting. This approach also extends to a governmental level, whereby government ministries e.g. for social development and the ministry for justice do not work together on disability.

This leads effectively to a siloed approach, where disability inclusion paradoxically operates in parallel to the spaces where this inclusion is actually meant to happen and where actual change is required. This approach, as the studies suggest, has multiple repercussions:

- It leaves these other mainstream spaces to an extent 'disability-free', lacking knowledge and understanding as to how to engage with disability and about the CRPD and its implications. This means that mainstreaming will effectively not happen:

*A main problem is really, that in our catchment area, there are a lot of NGOs, but none of them understands disability... they have often funds and political contacts that we do not have, but they do not include persons with disabilities...these NGOs could actually work much more efficient than us sometimes... (Participant, Jamaica)*

- Critical policies in multiple areas, for example social justice, are therefore developed, implemented and monitored without disability being actively considered.
- The lack of involvement in discussions on cross-cutting issues, for example on disability

and indigeneity or gender, means that any reporting on disability excludes critical issues or it may well be partial and ill-informed without adequate input and expertise from these stakeholders.

- Weak alliances with other organisations in other sectors that may also exclude disability, and which contribute to advocacy as well as practice efforts that are severely diluted when support by others is low or non-existent. This participant explains the exclusions by the women's movement in Guatemala:

*In general, there is a lot of machismo in all the country, in all the world, no? and issues specific to women and girls, do not want to be understood, because it is considered a way of dividing movements...in the capital city, there is also more awareness by the women's movement in general...and also that the women's movement has not wanted to get involved with women and girls with disabilities as part of its struggle. And this might sound tough to you, but for women, disabled women and girls are not considered women.*

**(Participant, Guatemala)**

Another participant from the Philippines illustrates how token and isolated disability-specific actions have scarce to no impact and may only be a temporary tool of silencing:

*Disabilities will never be eliminated, but the enhancement of the mainstream is what I want to be improved...To appease the (disability) sector, the most common approach is, "Ok, let's do some disability-specific services so that you will no longer complain (be noisy) a lot. We'll give you a 10% discount on public transportation, stop complaining, ok?" However, opportunities remain uneven. I still have to wait for 10 vehicles to pass before I can really get a ride. How does that really help me? So it is often really appeasing so as to silence us. (Participant, Philippines)*

Overall, this siloed approach often means that social transformation is scarcely happening as demanded by the CRPD in order to provide the conditions for

effective inclusion of persons with disabilities. The mantra 'nothing about us without us' is in practice not well understood.

### 3.2.8 Fragmented data and information

Article 21 of the CRPD denotes the right to freedom of expression and opinion and access to information, especially information that is fully accessible. This becomes critically important especially in times of crises, such as the recent COVID pandemic (see WHO, 2020). A mechanism of localization articulated by a number of authors in the scoping review of the literature is also the need for more efforts targeted at the local monitoring of the implementation of the CRPD. The idea behind this appears to be that local monitoring will include local perspectives; better identify local needs and react quicker to these; strengthen OPDs and local networks; and create capacity. A critical approach to this monitoring appears to be an emphasis on the generation of disability disaggregated data, mirroring calls in broader literature stressing the role of such data to hold governments to account and to inform advocacy (see for example Abualghaib et al., 2011; Bickenbach, 2011; Lang et al., 2011). In this regard, initiatives are mentioned in multiple contexts in the scoping review. For example, Dziva et al. (2018) highlight how the government of Zimbabwe 'also implements the CRPD through research and documentation of disability issues'. They describe commissioned research in 2013 by the Ministry of Health and Child Welfare to look at the living conditions of persons with disabilities alongside 'a comprehensive mapping for the lives of PWDs'. Other statements are made, including how the government of Zimbabwe also works with non-governmental organisations (NGOs) and state universities to conduct disability research to inform policy formulation and implementation.

However, it is important to note that these perhaps well-intentioned statements and measures meet a reality whereby the lack or absence of such data and capacity to generate it in the first place, especially at a local level, constitutes a major barrier, even in programming (see also Abualghaib et al., 2019):

*Yes, one of the barriers is the data...and maybe also research. We know research informs a lot, so research of course is tied to finances... I*

*mean we need data. That is another resource that if we have it, it can form our programme planning. (Participant, Kenya)*

Indeed, there is ample evidence to suggest that much disability data remains not only scarce, but that what is generated or drawn from censuses for example is frequently unreliable, including on the basis of varying conceptualizations of disability as well as methodologies (see for example Palmer and Harley, 2012; Altman, 2014). These become more complex problems at a local level in the global South, where complex socio-cultural framings of disability and also rights mean that one does not always know what is being measured (see Groce, 2006). In this regard, there appears to be a profound disjuncture between rhetoric and reality, between what is desired, and what is actually possible in the realm of measurement. This participant from Jamaica is emphatic about the need for useable local statistics as opposed to aggregate abstract numbers:

*We really urgently need data that people can use and understand data that says something about people on community level, not some abstract country statistics (Participant, Jamaica)*

Quality disability disaggregated information that is barrier-free and accessible to all, including people with visual impairments, deaf people or those with psychosocial disabilities is particularly scarce. So is information and data that is available in all local languages, including indigenous ones, and which would ensure that most of those who are ordinarily excluded can access information and communicate back to the systems and structures responsible for implementation. At the most basic level, this serves for them to even know what their rights are on paper and for local politicians to know what they are supposed to be doing:

*In these areas, rural areas, these departments, not much information reaches us so that we too can get involved in the area (disability). I think it is very important that they share information with us so that we can be a part of all of this, so that we can inform ourselves, to know more about our rights, but here, honestly, I do not hear anything, there aren't spaces where they tell me 'come, you are invited... and*

*we are going to speak about the CRPD, and what adjustments are needed in this space...in my village, none of this...and politicians... nothing, do not know where to start (Participant, Guatemala)*

This issue of accessibility of information is in need of much further research, not least because simply translating material does not mean that the information is culturally and contextually relevant and even intelligible. However, and this is a key finding itself, while the literature may mention the need for accessible information, it devotes far less time to actually suggesting how this can happen in practice in multiple heterogeneous contexts. Indeed, evidence from the studies highlights a landscape of fragmentation when it comes to disability disaggregated data, most notably at rural local levels on account of a number of reasons. These include:

- Scarce to no local data generation efforts, especially formal ones, for example by municipal authorities: this goes beyond disability to include even basic statistics, like the number of inhabitants in rural areas
- Lack of or no budget for data collection
- Local organisations on the ground, including OPDs, lack the tools, skills and also resources (financial and time) to conduct research and generate data.
- Lack of national efforts at collecting quality disability disaggregated data
- Disability-disaggregated data collected at a national level (e.g. censuses) is often of low quality

In all countries from which shadow reports were analysed, non-state actors commented on the lack of disability-disaggregated data in particular circumstances. This affects the ability of State departments to plan and design interventions to implement the CRPD. In Jamaica, the Centre for Investigation of Sexual Offences and Child Abuse does not collect disability-disaggregated data. Many shelters for women are physically inaccessible and provide little or no sign language access (CSS JAM 47972, 2022). Without disability-disaggregated data, it is very difficult to design an inclusive

intervention to meet the needs of Jamaican women with disabilities who are abused. In Guatemala, the Human Rights Ombudsman notes that the National Survey of Living Conditions does not collect disability-disaggregated data. Thus, in Guatemala:

*...the percentage of the population with disabilities in a situation of general and extreme poverty is currently unknown, reflecting in addition to the exclusion and marginalization of the State towards the population with disabilities, their disinterest in knowing the living conditions of this population, to implement the pertinent measures that ensure a dignified and quality life. (CSS GTM 24858, 2016: 7-8)*

Fragmented data and information impact the process of localization in complex and multiple ways that cross-cut the micro and the macro levels. Most particularly, they weaken local and regional advocacy efforts when actual facts are not available and when politicians may only listen to hard numbers rather than narratives or anecdotes. It also influences planning, budgeting and programming. Essentially, it reduces access to ground-level information on the realities of different persons with disabilities, especially those who are most marginalised, including women and indigenous people. Disability-disaggregated data is both an outcome of monitoring the implementation of the CRPD as well as a means to examine the reported situation of persons with disabilities. The absence of disability-disaggregated data reported in some countries is problematic for the design of interventions to implement the CRPD. The lack of basic disability statistics and registration of persons with disabilities impacts for example design and provision of targeted basic social protection, which in most cases excludes those in poor rural areas, outside the formal system:

*It is important to see the obstacles that exist when it comes to the national registry of persons with disabilities and their invisibilization across policies of social protection and public policies...the need for certification of disability, because this would permit the State to include person with disabilities in a social protection program (Participant, Guatemala)*

### 3.2.9 Socio-economic, political, cultural and legal context

What was evident was that CRPD and the process of localization exist within and are conditioned by a complex ecosystem that is highly heterogeneous and dynamic and that varies across contexts. In this regard, the process of localization cannot by any means be disassociated from these factors and processes, not least because they affect what can be achievable in practice and how. What we present below are the main emerging themes in our respective studies.

#### 3.2.9.1 Political issues

Political concerns cross-cut the three studies with substantial intensity. While, as we will argue, the political terrain is not the be all and end all of localization, it does condition multiple dimensions, including access to resources, accessibility to services, investment in infrastructure, and not least, a change in attitude towards more inclusive politics. A number of points stood out in the political arena:

- The disability agenda may be tarnished by partisan politics in some places more than others, whereby only party-aligned people sit on disability affairs committees, which means that they may not readily criticise government when rights are violated or things are not working. This meets a scenario of greed and corruption:

*...close to 15 years after ratifying the CRPD, it seems that we are still in square one because), the CRPD has not really been institutionalized. Furthermore, our political culture here is that if there are new officials, what they want to do is to make a name for themselves. They do not really examine or even continue on with the programs of their predecessors. Political ambition and greed gets in the way. They want to be identified with their programs- "This is mine, this is my program"- even if the new programs are really useless and worthless. (Participant, Philippines)*

- The political directorate is not always aware of the CRPD, often have not read it and do not know the content and its implications in their own sectors. This lack of knowledge is accentuated at the local and municipal level for example, where even national laws may not be known. These two excerpts from Guatemala, one from the interviews and one from the shadow reports, highlight this situation:

*At the municipal level, there are many mayors, who too, I imagine, do not know the CRPD... they do not even know national laws...I saw a disconnect from national politics, and I imagine that the CRPD results in the same thing, almost something abstract at a local level (Participant, Guatemala)*

*The rights of persons with disabilities are seen as a mere solution to problems of education, work, health, medicines and mobilization. They are not named as rights. The rights are not known five years after the ratification of the State of Guatemala [sic]. It [the CRPD] is an unknown text. (CSS GTM 23394, 2015:6) [SR1] [WJ2]*

- Laws are often made without consideration of the CRPD or the complexity of disability:

*Politicians often make laws without really considering the CRPD. They just make laws that can be attributed to them. They don't really understand disability. If they really did, then a lot could have changed already. That is why I really think that the definition of disability should be made into a law. Everything that we need, even the matter of assessing persons with disabilities, all these should be made into laws. (Participant, Philippines)*

- Disability may not be seen as a priority by local and regional politicians in particular, or they may be indifferent to it, which means that it does not translate into anything in practice, for example in provision of local services. These quotes reflect these concerns:

*They speak about being able to implement, to struggle so that the rights of persons with*

*disabilities are respected, but it is only about saying it and that's it, and as we have always discussed with other companions, persons just see it as a way of obtaining some benefits and nothing else...Sincerely, they are not interested, because if they really were interested, there would be something like calls for projects, spaces where we could be invited, to be able to participate, to speak about this (disability), but in reality there isn't anything...in my village there is nothing of this...they always do propaganda and all of this to obtain money and it never anything that is worth the while. (Participant, Guatemala)*

*We have really always the same politicians, one or two, dealing with disability...the rest of them do not know anything about the field, or are not interested... (Participant, Jamaica)*

This quote from the Philippines further expands on this, highlighting how even applying the concepts of the CRPD can be beyond the competence of local politicians and service providers:

*The CRPD can be realized by using the principles of CRPD. These can be enshrined in the totality of our programs, these are where you can translate these. It is rather easy to read the CRPD, but how to apply the CRPD in our local context lies the biggest problem of implementers. They cannot simply translate the CRPD because the concepts are rather broad. (Participant, Philippines)*

- Marginalisation of OPDs and engagement of consultants with no disability expertise on disability matters, reflecting a delegitimization of persons with disabilities in even speaking about and representing themselves and their own realities:

*When legislation and documentation or policies or implementation plans are drawn up, it often happens that the government appoints some consultants to do that work, and then ...after the work has been done, the document then gets sent to our organization and others like us... to*

*give input then it often happens that people with disabilities or us as organizations have to almost re-write the document to get it in line with the CRPD. It gets referenced, but the rest of the document it doesn't even look as if the consultant has ever heard of it, and then we have to provide that input free of charge, while we are not government funded but it's in our interest, it's in persons with disabilities interest to give the right input and to make sure that the correct definitions and everything is used because from there comes reasonable accommodation budgets and so on...so that is quite a hurtful point I must say, because it feels as if government doesn't have respect for persons with disabilities, and the organizations and then for the money part it goes to the fancy consultants and when the real work needs to be done then it comes back to the sector.*

**(Participant, South Africa)**

- Some countries and their governments may see the CRPD as a burden because they have to spend funds for example to make public places accessible, something they may not want to prioritise. This meets a mentality of offloading disability onto NGOs and a context of corruption and pillaging of public funds in others:

*I think the problem is that the localization of the CRPD, some people think that it should be a responsibility of the NGOs and organisations for persons with disabilities. I think the government should also play a major a role, like let us work together so that the CRPD is localized. Like to depend 100% percent on the donor's support, I don't think it is fair. I know that the government will say there is no money. What makes me angry is that sometimes there is no money to provide say assistive devices or do something for people with disabilities, but you look at the news you see that there is so much money that is missing? How? because there was no money?*

**(Participant, South Africa)**

- National politics and approaches averse and even antagonistic towards institutions such as the UN:

*In the context of Guatemala, at a political level is very complex, where even in the work of the UN system, one needs to thread with much care when it comes to dialogue with national (political) actors.*

**(Participant, Guatemala)**

- Lack of political will and commitment especially at local level: these are critical barriers, because without these, little can in practice be achieved, and disability policy can remain confined to paper. For example, in South Africa, while there are government departments that support the rights of persons with disabilities, according to non-state actors, there is also a prevalent lack of commitment to realising the CRPD. This is illustrated in this excerpt from the shadow report:

*While some government departments actively support disability rights and effectively liaise with disability organisations, the majority seems to be engaged in a "tick box" activity; wishing to be seen as consulting, but lacking political will and commitment.' (ICO ZAF 30270, 2018:3)*

This participant in the interviews, illustrates how disability itself is too often seen as a competing priority and consequently dropped:

*The CRPD has contributed towards the government acknowledging that there are indeed barriers. The problem, however, are the measures or steps taken to address or even eliminate these barriers. There is a huge gap in this regard. The usual answer of the government is, "We know that, but sorry, we have other priorities at the moment."*

**(Participant, Philippines)**

In the scoping of the literature, Lang et al. (2011) are categorical in highlighting a scenario of disjuncture between policy formulation and implementation, sustained by hurdles such as the lack of coordination between different ministries on disability issues,

scarcity of reliable data and lack of engagement between national and local government. Chibaya et al. (2021) report how their participants felt that politicians ‘ignore disability issues’ in a context where all disability issues were confined to one ministry, making it impossible to integrate them in others, but even more basically relegating disability to a separate space. Mahomed et al. (2019:341) paint a rather grim picture, even in places that have shown much initiative to ratify the CRPD with correspondingly ‘good disability policies’ on paper:

*Even where the CRPD has been ratified without reservation, such as in Zambia, lack of political will or technical expertise have meant that provisions such as those relating to legal capacity remain unrealised...Even where disability policies have been developed, there is evidence to suggest that lack of prioritisation, capacity-building or adequate resourcing can hinder the realisation of actual positive change.*

- Lack of funds for implementation: this is a serious concern given that the localization of the CRPD as emphasised above, is not a costless exercise. Shadow reports from Guatemala, Jamaica and Kenya stress the costs of a rights-based approach to disability and the need for funding to decentralise services to persons with disabilities and how these funds are rarely available, and in the quantities required to do this effectively. The Malawi report, for example, highlights a dramatic lack of funds in the country, where there are only 5 sign language interpreters in the whole country. This means that deaf people are effectively isolated. This quote from the Philippines also clearly explains the budgetary problem:

*I believe the CRPD is important. The problem however is in bringing this down to the community level. The excuse that is often cited is that there is no budget provided by the national government. There are indeed a lot of good laws, but these do not come with commensurate funds. (Participant, Philippines)*

This participant in Guatemala is categorical in stating that investment in disability has been below

negligible, too often without even a designated budget:

*This is what Guatemala does not have, if we speak about economic resources, there is no specific budget assigned. When we look at how much the State has invested in these last years in persons with disabilities, realistically, also because these things are not documented, or because the criterion of inclusion is not disability-specific, probably the percentage is 0.000 something...its a very small number... even with having the disability commission (CONADI), which often does not even deliver on its role, with its mandate, does not have a solid capacity, or a board with a recognized interlocutor in many national spaces (Participant, Guatemala)*

- Problems in devolution: devolution of power, administration, service provision and finances from national to local level appears to be a key generative force for localization of the CRPD. In some cases, nationally determined laws and policies mandate specific actions at a local level. The political structure of some States (particularly those with a federal structure) means that power is devolved to territories/states/provinces (regional level) which determine their own policies and legislation that may impact on the localization of the CRPD. A wide array of services and administrative tasks are devolved to both provincial and local government level that can localise the respect, fulfilment and protection of the rights of persons with disabilities. Another aspect of devolution from national authority level, is that of devolving the power to budget for and finance interventions, as seen in the periodic report from Spain (CRPD/C/ESP/2-3, 2018). However, non-state actors also warn and give evidence of disparities in interventions for persons with disabilities when regional and local level authorities determine their policies, plans and legislation independently. For example, a South African shadow report states that:

*Significant disparity exists between subsidy levels at provincial level (responsible for implementation). In effect, subsidies for*

*the same services vary between provinces creating inequality in service delivery. (ICO ZAF 30270, 2018:21)*

The following participant lays out a rather grim scenario at a municipal level. Making reference to the municipal offices for disability, an initiative promoted also by the disability council, he highlights how despite all good intentions, micro-politics and the peculiarities of local contexts often take over:

*Without doubt, out of 105 municipalities, how many of these have personnel working with a budget, with a plan?...there would need to be a unit that manages them, and so the achievement of rights of persons with disabilities is low...you can have 200 or 400 of these disability municipal offices that would cover the whole country, and I would dare say that in the highest percentage of them, it wouldn't work, because they are only there as a figure...then you have the mayor, you work with him for 4 years, sensitize him abit, and then the next one comes and destroys everything related with the previous one... and on top of this, persons with disabilities are not seen as productive citizens, but objects of charity. (Participant, Guatemala)*

- The policy making process, including lengthy and bureaucratic procedures, impact the localization process and also the level of timeliness and responsiveness.
- Lack of knowledge of technical issues and language by smaller rural OPDs, especially indigenous ones, which limits the ability to communicate on political issues. These meet, gendered and other terrains of discrimination, including racism. This indigenous participant explains how:

*There are many spaces where one does not feel good to be able to speak, because people there speak very technically, the people there are supposedly very educated on the subject...sometimes I have been invited, and I do not understand anything they are talking about because they are very technical...and I have been able to*

*study, but others....to be able to get involved in these political spaces...it has been difficult being a woman with a disability, they always push you to the side... (Participant, Guatemala)*

- Tendency by politicians to look at persons with disabilities and OPDs as recipients of charity rather than genuine participants and partners in the governance process and productive citizens with rights as intended in the CRPD:

*This is a problem come election time... and to add to that, we are often seen as not contributing to society. People often think, "Why are we giving our taxes to them if we ourselves are in dire situations?" That is one barrier, we are seen as beneficiaries, we receive assistance, but we are not really contributing to the economy...A lot has to do with the attitude of the incumbent (officials/ politicians). By and large, they are still in the welfare concept. They haven't really transitioned to the rights-based approach. They still see it (disability) as charity. (Participant, Philippines)*

- Priorities at the local level are often different from national ones, which means inconsistency in implementing the CRPD
- Traditional politics in many local contexts, especially rural areas in the global South are top down and patronage driven: this implies that rather than a politics of rights, what drives the agenda are tokenism, favours and personalismos. In fact, findings from the interviews highlight the multiple efforts that go into trying to warm up to local politicians- politics of favours not rights- personal choice rather than obligation.
- Lack of accessibility (see above): A common complaint in the shadow reports is lack of accessibility, of physical infrastructure, of transport and of communications among others. Not only are places such as rural health facilities and means of public transport physically inaccessible, but also in some cases, State structures, including at local level, perpetuate the situation by not acting on the situation even when there are violations and illegalities. For example, in South Africa:

*South African Disability Alliance (SADA) is also concerned by the fact that many municipalities (local government structures) are still issuing licences to transport service providers and operators who do not have accessible busses /services. (ICO ZAF 30270, 2018:15)*

- No evaluation: one major barrier is that there are no evaluations of progress as well as impact of any initiatives vis-a-vis the CRPD and no corresponding changes. This participant in Guatemala articulates the losses that come with this:

*There isn't a clear mechanism of how to proceed with this evaluation, of how the State should respond or inform in regard to the CRPD, and that is another barrier, virtually nothing is evaluated (Participant, Guatemala)*

### 3.2.9.2 Programmatic sphere

The findings from the study highlight how the CRPD and its localization encounter barriers in the process of programming. In the Philippines, persons with disabilities are reported to often be excluded from civil protection and humanitarian responses in times of emergencies (IFL PHL 30094, 2018). The Jamaican shadow report indicates that as yet there is no independent monitoring mechanism in the country (CSS JAM 47972, 2022) and in South Africa there is very limited availability of places of safety for children with disabilities who are abused, neglected or abandoned (ICO ZAF 30270, 2018). This echoes findings in other studies (see for example Hussey et al., 2017; Enfield, 2018), not least in how the CRPD may be lost in translation when it comes to programs developed on the ground, for example when budgets do not reflect what would be needed for efficient implementation:

*This is also true at the local level. Many people do not have work, the local governments do not have good sources of local revenue. How can they provide services? (Participant, Philippines)*

*They often say that while the national government brings down programs, they do not provide the funds. There are a lot of good policies but are not really funded. So how can these be implemented? (Participant, Philippines)*

Indeed, developing programmes requires funds, and a carefully crafted budget that is sensitive to and responsive to the needs of very specific contexts. In other cases, for example in a South Africa shadow report, one can witness instances whereby provinces budget independently of each other, which means that there is a variation in subsidies of services across different localities. In sum, in some places they can access some things while in others they cannot because of differences in budgeting. Even more basically, there may be a lack of a programmatic strategy. For example, local councils may be appointed in 3 urban districts, have a small number of disjointed initiatives here and there, but there is no unified strategy. Importantly, much depends on the individual will of a person, for example a mayor to set up any programs.

### 3.2.9.3 Legal terrain and justice

While the existence of legislation, policies and plans does not guarantee implementation of the CRPD, they can provide an enabling framework which OPDs and civil society can use to hold the State to account. For this reason, laws, policies and other state commitments are considered as a possible resource for the localization of the CRPD. As with other international human rights conventions, national governments and central state authorities are responsible for entrenching the implementation of the CRPD into their domestic systems and context in order to meet their obligations. Rivas Velarde et al (2018), in their exploration of Article 25 of the CRPD with reference to the health and well-being of indigenous persons with disabilities, claim that the transformative vision of the CRPD can only be realised through changes in domestic law, policy and systems. As Faye Jacobsen (2022: 1) points out, in international law 'human rights are legally binding at all levels of authority within the contracting states' parties. This includes local government'. Thus, local government is legally obliged to respect, protect and fulfil the rights of persons with disabilities in signatory states, as well as frequently being the site at which human rights should be implemented in a manner that is contextually appropriate with regards to culture, resources available and the situation of the target population.

However, in practice, the situation is extremely complex as evidenced across all our studies. First of all, adapting local law as demanded by the CRPD is difficult, not least because it includes the whole existing body of law. It means much legal as well as human and financial

resources to be able to do this, and not least, political openness and commitment to the process that may not always be present:

*Its application (the CRPD) is very difficult, and in most cases, being able to push for inclusive public policies, to develop institutions, to assign a budget to advance the content to align with the preconditions of the CRPD, really is very difficult (Participant, Guatemala)*

Another participant in the Philippines goes on to explain how domestic laws often prevail, however dated they may be and whichever conflicts they may have with the CRPD:

*If the convention is adopted, domestic legislations which are restrictive will somehow be amended or repealed (if these are in conflict with the convention). But the ruling of the Supreme Court [says] that the treaties should harmonize with domestic law. But if there is conflict, domestic laws should be prioritized. However, if the domestic law is dated, legislators should examine what's the latest [and its applicability]... but as a general rule, domestic laws prevail. (Participant, Philippines)*

This quote from a participant in Guatemala, highlights how even national policies themselves can go against the rights of persons with disabilities as laid out in the CRPD and can promote and maintain charitable as well as disabling approaches:

*The legal frameworks are totally violating if we see them in light of the convention, they violate rights, they are not legal frameworks that permit the realization of rights, they are legal frameworks that day by day, restrict the rights of persons with disabilities...Over the last years, there has been no progress in legal matters that improves the context of persons with disabilities and the valid legal frameworks, even if there are various laws that address the subject of persons with disabilities...and so there are various legal holes and there are legal laws that themselves promote stigmatisation, discrimination, charity towards persons with disabilities. (Participant, Guatemala)*

This same participant went on to highlight, how in Guatemala there is a lack of legal identification of

persons with disabilities as rights-holders in need of targeted protection, and where instead they are pooled in with other populations.

The findings highlight how there is a lack of consistency as to who in practice is responsible for ensuring that all relevant existing bodies of law within a country are adapted to meet the obligations of the CRPD.

It is worthwhile mentioning here that OPDs often lack legal knowledge and legal support which means that they struggle to fulfil a monitoring role. This legal knowledge is also required to be able to identify all pertinent laws in every area that need to be harmonized, including laws that themselves may discriminate against persons with disabilities:

*How can a DPO actually understand the full legal text? We are supposed to give input to all kinds of reports, but we do not have a legal counsellor. What we need is access to legal advice first! (Participant, Jamaica)*

Related to this, at a national and local level, one critical problem is that the legal profession remains largely uneducated in disability. Interviews from some countries more than others illustrate multiple concerns, including: lack of interest in disability; scarce knowledge on different disabilities and the barriers that are faced; and limited attention to interactions with other dynamics of oppression and inequality, for example gender or indigeneity. At an even more practical level, there are dramatic gaps when it comes to pro bono legal services. One major point here is the fact that persons with disabilities are hardly in a position to seek legal redress on account of their poverty, and because of the multiple contextual dynamics and factors. Indeed, a number of critics (Grech, 2015; Soldatic and Grech, 2014, 2022) highlight how poor persons with disabilities often do not have the resources to claim their rights, for example to reach a major city for legal support, and importantly do not have time or financial means to sustain a court case because basic needs and survival need to be prioritised. Shadow reports from three of the five countries comment on difficulties related to access to justice for persons with disabilities, especially those who are victims of violence. As a South African civil society organisation explains:

*...despite the legal framework, which is in most part aligned with the Convention, not enough is being done to prevent violence against persons with disabilities and barriers to accessing justice persist once a violation has occurred, which further compounds the injustice and renders persons with disabilities even more vulnerable.*  
**(ICO ZAF 30105, 2018:5)**

The barriers to access to justice mentioned in reports from the Philippines, Guatemala and South Africa, include lack of awareness of the rights of persons with disabilities, lack of accessible physical infrastructure of courts, unavailability of sign language interpreters and slow progress of cases through the legal system.

Findings from the interviews sustain a view of the situation as a tragic one where even cases of rape are not even reported and much less investigated by police, meeting often ill-informed or generalized assumptions about persons with disabilities and their capacity to testify in a justice system, virtually barricaded to them:

*There's a lot of lack of access to the justice system, it's in our gender-based violence and program, support programs for woman and girls, one of the action that takes most of our time resources and which is not difficult, not easy to fund is... the fact that various woman and girls are raped and they don't get even as far as the support of the police to make a case...simply because of the non-willingness to go the extra mile, non-understanding... of how people with certain impairments can actually go to court and testify, wrong assumptions **(Participant, South Africa)***

#### 3.2.9.4 Poverty: where basic needs dominate

Critics highlight how the power of the CRPD is constrained in practice by multiple factors, not least the poverty and inequality it meets at a local level, and what life in poverty means for persons with disabilities, especially in rural areas (Grech, 2009). The literature scoped as part of this study provides indications at various instances of the hurdles faced: '...persons with disabilities in the area had limited access to basic services such as education, employment, and healthcare'. (Opoku et al., 2016)

The process of localization is conditioned in multiple ways by poverty in its full complexity, multidimensionality, heterogeneity and dynamic nature. This means the need to engage with social, economic, political, cultural, ideological and religious dimensions, including the complexities of livelihoods, infrastructure, alongside framings of disability in context. All these interact with multiple other dimensions to impact the extent to which the CRPD can be localized, how and to what extent, and with what effect in multiple areas. In particular, there is an emphasis on poverty that affects everyone indiscriminately, but whereby the barriers are intensified for persons with disabilities, while creating new obstacles. The following quotes from scoped literature, provide information on the extent of these poverty related obstacles:

*Whilst inaccessible infrastructure may contribute to hindering PWDs from securing employment in government and private companies, it may not be the paramount reason for the unemployment of PWDs. Zimbabwe is a low income country that is experiencing economic difficulties, which have resulted in very minimal functioning of the industry and an unemployment rate of over 90%. **(Dziva et al., 2018)***

*PWDs are excluded in matters of concern to them in society owing to inadequate assistive devices and inaccessible structures and environments. **(Dziva et al., 2018)***

This situation of poverty and the obstacles become even more complex and dire as indigeneity and other intersectional dimensions are factored into the equation, creating a complex web of hardships and oppression:

*The manifestations of poverty that were observed and narrated by Aboriginal and Torres Strait Islander people were significantly more severe than those reported by Purepecha Mexicans and Māori. Lack of economic resources determined the ways in which indigenous peoples live; for example, the sharing of unsafe accommodation without a proper infrastructure, which increases the risk of communicable diseases. **(Rivas Velarde et al., 2018)***

This poverty, as the following quote illustrates cannot be ignored, because it impacts even the extent to which even advocacy and awareness raising are possible:

*All participants identified limited financial resource as the leading cause of the challenges the persons with disabilities experience in Namibia. The persons with disabilities who held positions of authority could not conduct awareness programmes due to lack of funds. (Chibaya et al., 2021)*

Interviews in this study highlight how practical needs often dominate over strategic ones in contexts of poverty and inequality, which means that these may come to even compete with each other. This has serious implications including what realistically can be included and targeted and whether 'higher order' needs and rights are of consideration in contexts of extreme deprivation. More basically, poverty influences how the process of localization happens, what can be invested, the barriers it meets on the ground, and what can realistically be achieved. Rivas Velarde et al. (2018) highlight a continued trend of continued imposition of policies on indigenous people and also how programs showcased by northern INGOs for publication as well as best practices do not always reflect realities on the ground. This does not include harsh realities on the ground, where despite the changes in rhetoric, there are concrete barriers to participation by OPDs in debates and practices, not least on the basis of poverty and inequality. These, if anything, need to be rendered more visible. This participant from South Africa explains the conundrum faced by poor persons with disabilities with limited means vis-a-vis participation in advocacy and programmes:

*Mmm...but also remember we live in a very difficult time, you cannot expect me to be at an awareness session for the whole 50 minutes knowing very well that within that 50 minutes I would have made maybe R150 that I can buy food with later on for my family. So maybe that's why not everyone will be there because some are looking at time they are wasting at the intervention sessions and the fact that they need to make money out there and they have an impression that "being here will not benefit me in any way." (Participant, South Africa)*

This participant from the Philippines addresses the dire need to strengthen livelihoods before expecting anything else:

*What we should quickly address is to ensure that people have livelihood and employment. This will stabilize their economic condition. If they have income, then they will be able to provide for their other needs. (Participant, Philippines)*

In Guatemala, this participant highlights how even hunger and basic medical needs dominate in rural areas left to their own devices:

*I understand that there are basic needs to satisfy, people are hungry, they do not even have dignified living conditions, and because of this, people do not see much sense in a basic political education, for example..because people are more preoccupied with what they are going to eat today or that they need their colostomy bags or their catheters...daily needs, the minimum that allow you to survive..and so, in such a context, the CRPD does not make much sense at an individual level...in the interior of the country (rural areas), nothing much has changed from the approval of the CRPD...disparities, slavery... because here in Guatemala, slavery still exists...and so I believe that what happens is that in the rural areas and even more remote areas, the State does not exist. (Participant, Guatemala)*

This participant in Jamaica was rather direct, how in such dire circumstances and the quest to merely survive, the CRPD becomes superfluous if not meaningless:

*You cannot go out and tell people about this CRPD, if they are struggling to make ends meet. They need to survive. Who cares about a convention...? (Participant, Jamaica)*

This poverty exists within and is also influenced by broader geopolitics, for example the current war in Ukraine which is pushing up prices globally, including of food, which means that localization cannot be stripped of a geopolitical analysis, not least because those most impacted are those weaker positioned to withstand stresses and shocks, among them persons with disabilities.

### 3.2.9.5 Cultural, attitudinal and historical dimensions

One of the key barriers to localization are negative attitudes and responses towards persons with disabilities, in some places more than others. These are very well articulated in disability studies (see Oliver, 1990) including research focused on the global South (see Kamenopoulou, 2018), and upon which much of the rights discourse is built. Negative attitudes remain insidious, especially as they bind through complex folk beliefs, for example about the provenance of disability in indigenous areas. (see for example Groce and McGeown, 2013; Grech, 2015). These quotes from the literature scoping review and from interviews are illustrative:

*According to the participants, most people thought disability was a curse arising out of the evil deeds of their parents or family members. Due to this perception, people did not want to support or associate with persons with disabilities... Several participants expressed their discontent about being reduced to worthless objects incapable of doing anything beneficial in their lives. (Opoku et al., 2016)*

*Stigma and discrimination have subjected persons with disabilities to isolation, marginalisation, and loneliness, resulting in abuse, violence, neglect, labelling, ignorance, and fear. All participants experienced stigma and discrimination from family or community members. (Chibaya et al., 2021)*

*Based on conversations with other groups, there is a lack of knowledge when it comes to understanding how they can access services in their communities. Their mindset towards disability hasn't changed. There are still people who believe that disability is gained because of sin...done by a person. For faith-based individuals, they see it as a challenge that was given by the Lord. (Participant, Philippines)*

These negative attitudes may also be present within families, whereby persons with disabilities can be excluded from decision making and marginalised in access to resources (Opoku et al., 2016). The implication, though, and which is hardly considered in the literature scoped in this review, is the need to

consider intra-household factors into the analysis of localization and to work on corresponding measures to address these.

Cultural dimensions have an incredible impact on the process of localization as do contextual and historical ones. This is because disability is framed, lived and also survived within these contexts with their own baggage. These attitudes are critical in the process of localization because ultimately they influence behaviours, that is how people respond to disability and in turn what it is realistically possible to achieve on the ground. They also affect the level of resistance to change. This participant in South Africa navigates the difficulties and adaptations in operating in contexts where folk beliefs and practices still dominate:

*We also had to work with the traditional healers because they are the ones also who do the diagnosis regarding disability in a traditional way. We just say "you know what, we understand that you know from your perspective this is the possible cause of disability, but from the medical perspective this is the cause of disability." And you know we work together with them so that you know, if I can make an example, you find that each child was given an assistive device but the child is not using the assistive device now. You know, then we say because you can communicate with the ancestors please do communicate with them that it is crucial for this child to use the assistive device." (Participant, South Africa)*

This participant from Kenya further elucidates the limitations of the CRPD in contexts where persons with disabilities may not fit the cultural norm:

*I think the cultural aspects like people with disabilities face discrimination around the world and some cultures might be still less inclined or less likely to really change mindsets about disability and persons with disabilities... the CPRD is a facilitative treaty...but quite often people with disabilities are left out, because they do not conform to what society sees as the norm. (Participant, Kenya)*

Findings from the study illustrate a scenario whereby these beliefs, including stigma, influence

whether local politicians will take initiative at all to protect the rights of persons with disabilities, or whether violations are reported, if the victims are not even seen as fully human. In Guatemala, interviews also highlight how history, in this case one of genocide, comes to bear. Participants stressed how 36 years of civil war enshrined a culture of fear and silence, whereby it is not common to get involved in problems, and much less to report them because this can objectively lead to harm or even death. This challenges the assumptions made in the CRPD that people may be willing to report violations in the first place. It also influences if and how advocacy is possible at all, if protest is met by threats and violence. Even more basically, cultural dimensions influence how advocacy is done and the groupings themselves and how these are reflected and represented:

*This may sound repetitive to you, but to me, the very particular history of Guatemala has led to a society where common people assume a very reserved attitude...very submissive, very obedient, very much not wanting to think because they are afraid or because they have been taught to not think. Yes, here, thinking is punished with life, that is, if you think, they kill you. (Participant, Guatemala)*

But taking a step back, as Grech (2015) suggests, the notion of rights itself may not be quite intelligible in contexts where rights violations are so normalized (and perhaps even expected), not least via a poverty that disables and dehumanizes, that the idea of having rights that can be claimed is far from common in some places. These barriers and obstacles remain in need of much critical literature in the context of the CRPD, because rights are ultimately lived at a local level:

*I would think that human rights are universal...I am convinced...but what happens is that the understanding of human rights is not the same in all places. (Participant, Guatemala)*

### 3.2.10 Representation issues

The issue of representation is as important as it is complex, and some of these complexities have been discussed in the literature (see for example Jan, 2015). Findings from the 3 studies lay out a panorama of challenges when it comes to

representation of persons with disabilities, not least whose voices and perspectives are actually heard in debates and interventions. In the section above, we have already presented some of the main concerns when it comes to OPDs that are far from united or homogeneous. A number of key issues emerged, notably in the interviews:

- OPDs are not always seen as representative especially at a local level: indeed, it was suggested that persons with disabilities, notably indigenous and rural people do not feel represented by privileged urban non-indigenous OPDs that hardly know their realities, their needs and demands. This indigenous participant expressed frustration with this situation of being spoken for:

*...in OPDs, I believe there are always people speaking for us and this is not something good. Because they try and represent us and not us so that we would be able to show what our reality is as persons with a disability...I have had enough of this...they know nothing about us. (Participant, Guatemala)*

- In some situations, they may be politically aligned with the government of the day, which means that they will not easily criticise disabling policies and practices.
- There are only few new champions especially from local and rural contexts: indeed, it appears that the voices heard at national and even more so at international levels are always the same people. These may be disengaged from the realities they speak about, and may also not always be the best people to carry these local concerns forward either.
- In many instances, poorer and more isolated OPDs cannot even cover the costs of transportation and lodging to attend meetings, for example those with the disability council. This participant from Guatemala explains the situation:

*We have had events and a person needing to travel from one department to another, maybe in terms of distance they are not much, maybe 60 or 80km, but there is no*

*allowance to pay them (rural OPDs) to cover lodging, food, transport etc. because it is very far away...all because there is a very urban centralised view...and obviously, this limits a lot the participation of people with disabilities.*

**(Participant, Guatemala)**

- Hierarchy of impairment: how society is structured, allows for some to thrive more than others and for their voices to be heard louder. This means that certain groups, for example deaf and blind people may be more powerful in some countries, while in others, without adequate support such as sign language interpretation, persons with physical disabilities may be in a stronger position. Among these, people with psychosocial disabilities are the most disadvantaged and rarely represented on their own terms. Overall, this hierarchy intensifies as it meets other lines of inequality, including gender, poverty, rurality and indigeneity. Indigenous voices and realities are hardly known and much less represented, and when spoken about, too often simplified and generalized without grounded knowledge.
- Capacity issues: both organisations of and for persons with disabilities may lack adequate capacity, including technical knowledge, lobbying capacity and human resources to articulate the needs and also represent persons with disabilities. This is especially the case in higher level platforms and fora where capacity needs meet those of social and linking capital, which organisations, especially those at a more local level, rarely possess.
- Ageing advocacy population: many disability advocates are senior people who have been on the scene for a long time. This means that other, notably younger voices and their needs are not adequately known and represented. Critically, it implies that there is scarce training and preparation of future advocates who will need to represent themselves and their own generation. In a number of instances, this was attributed to lack of will by younger people, motivated also by the absence of a common cause:

*I think there's a bit of a gap between the young leader and the much older leaders and there's kind of like nothing in between... there's not that strong lobbying we used to have in apartheid years when we had to fight a whole system...we do not have the human resources, like young people with disabilities who are active...like if we die now we do not have people to take over, so for that it is lacking, grooming of the future leaders with disabilities...*

**(Participant, South Africa)**

- Some representatives may not really understand the CRPD and its implications and have not gone far in terms of the harmonization of concepts within the CRPD.
- Encouragement of a more macro approach to monitoring with scarce local engagement, basically a fig leaf for politics.
- Internal problems: in many countries a disability council, commission or the equivalent is tasked with overseeing the implementation of the CRPD and monitoring. At a regional or municipal level, one may even find disability offices set up within municipal offices for example. However, findings from these studies, notably the interviews, highlight how these institutions are often dogged by multiple problems including: lack of technical knowledge (including on monitoring or the CRPD itself); incompetence; corruption; misuse of funds; power struggles; no representation and active exclusion of poorer rural disability organisations, especially indigenous ones. In sum, those meant to play a critical role in the localization of the CRPD may themselves be a core part of the problem. This quote from Guatemala expresses sentiments about a disability council perceived as one that has coopted the disability space without delivering the goods and which disempowers persons with disabilities and their organisations:

*The council (CONADI) believes that its survival is at stake, so it resents persons with disabilities becoming empowered and becoming activists, to communicate with ministers and governors, because the*

*CONADI thinks it is its executive role...it has a protagonism that is hegemonic...but the CONADI is not the only one...but it has closed all the spaces for civil society participation, in such a way, that if organisations take their own initiative to speak to congress, with ministers, these will always tell us 'but agree with CONADI' and this shows that the public opinion is that it has the voice...but they are incompetent, even in training they provide... they do not know the subject areas... the same CONADI is a barrier in our progress*  
**(Participant, Guatemala)**

What cross-cuts these is an assumption in the CRPD and its national interpretation that merely setting up such a post or role within these institutions will translate into local implementation of the CRPD and that these will impact other levels of relevance. This is not dissimilar to the assumption that having persons with disabilities or OPDs from privileged contexts round a policy discussion table will translate into change for those in poorer areas- in reality, disconnected- existentially and practically (see Grech, 2015; Meyers, 2018 for more on this).

The scoping review of the literature reveals how there are no follow up studies evaluating the effectiveness and impact (if any) of such institutions, positions and measures, as well as their sustainability, leaving a number of questions hanging. These include: do such posts renew with a change in government? Do they have a budget to work with? Do they even know the realities confronted by those on the ground? Are they representative of such concerns and voices? Are they familiar with disability rights and how these fit the broader policy landscape? Even more critically, what resistance is there at other levels of governance (for example other ministries), especially when disability may well be a marginalised policy area or even discriminated against? Another observation here is that most of these focal points are located in urban places, especially at a regional level, the implication being that rural areas are hardly represented and covered. In a nutshell, there is profound urban-centrism. This lack of focus on rurality constitutes major obstacles to policies such as those designed to safeguard employment of persons with disabilities

in contexts where unemployment is across the board, and where livelihoods are contingent on hard physical labour. For example, grants for persons with disabilities are often bound to formal labour, which can exclude the bulk of rural people who more often than not work in the informal sector and are hence unregistered (see Grech, 2015).

### 3.2.11 Intersectional terrains

Implementation, monitoring and reporting and indeed the whole process of localization meet extraordinary barriers when intersectional dimensions are factored in, resulting in complex and often interacting dynamics of inequality. The scoping review reveals reasonable attention in the literature to how these barriers, not least discrimination are accentuated for some segments of the population with disabilities, including women, children, refugees, internally displaced people, those in rural areas, people with psychosocial disabilities and indigenous peoples. Many of the shadow reports, too, highlight the difficult situations of particular marginalised groups of persons with disabilities, including lack of access to services, abuse and exploitation, exclusion from community and political participation, greater prevalence of illiteracy and increased poverty. For example, in Kenya:

*Recent reports have indicated that cartels are now using children with disabilities as beggars in urban areas. They are not fed or paid. The children are kept in inhumane conditions to worsen their disabilities as these [sic] guarantees the cartels more money. (CSS KEN 21296, 2015:22)*

Similarly, the intersection of geographical location and albinism is a source of life-threatening danger in Kenya:

*There are currently no specific measures in place to protect persons with albinism from abduction and murder and other discriminatory practices.... The greatest threat experiences are in the border locations with neighbouring countries where there are cultural beliefs that body parts of persons with albinism can be used in cultic practice and in the cure of such diseases as HIV/AIDS. (CSS KEN 21296, 2015:17)*

This makes implementation and localization of the CRPD even more difficult, especially when policies and resources are not equipped to adapt to these different realities, for example in the case of access to health care and the interactions with gender-based discrimination. The following quotes from the scoped literature and interviews illustrate the obstacles to a genuinely inclusive localization process, meaning that some more than others are likely to slip outside the net, with serious repercussions:

*Regarding children with disabilities, there is persistent prejudice and discrimination against them, mostly in rural areas, because of entrenched cultural views that disability is a result of punishment from God and ancestors* **(Dziva et al., 2018)**

*Race-based attitudes were perceived to be a barrier to health as they affect quality of life, social mobility and social inclusion. Discrimination affected the mental health of indigenous persons with disabilities and their feelings of self-worth. Feeling discriminated against was often linked to anxiety and uncertainty about health entitlements.* **(Rivas Velarde et al., 2018:1437)**

*In terms of women...you know that if you are a woman in a rural area, you are not married and you do not have a child it will be very difficult to access land for housing or land for agriculture.* **(Participant, South Africa)**

*And then the identity of being a woman or a girl-child comes in. Their role is seen as simply being confined in the house, that they are expected to be passive. They do not see many women with disability role models. So they come to believe that this is what the situation should be. Women and girls with disabilities will simply believe and accept this as their reality.* **(Participant, Philippines)**

*There is a lack of focus on rural areas. In indigenous people's communities, many are not included. And then you can add in their being women or even girl children.* **(Participant, Philippines)**

Bound to the issue of intersectionality, one area that deserves particular attention is that of indigeneity,

conspicuous in many places by its absence. Indeed, what emerges in the scoping review is the lack of consideration of these populations through targeted legal protection for indigenous persons with disabilities. This marginalisation of indigenous issues is entrenched deep in the architecture of the CRPD itself. Harpur and Stein (2022:173) express how over a six and a half year period, the CRPD committee 'fail either to engage with indigenous issues or, when they do reference these populations and their needs, are inconsistent in approach'. They go on to stress how:

*'...despite ample opportunity, the CRPD drafting negotiations fumbled several opportunities to recognise the heightened vulnerability and needs of indigenous persons with disabilities within a number of articles. In consequence, indigeneity is not mentioned in the body of the CRPD and appears, only once, in the CRPD's Preamble'.*

The implication is that the CRPD is lacking when it comes to the coverage of and protection of their rights, not least because even at the most basic level, there is no access to the CRPD as well as other critical material, for example in schools and professional development in indigenous languages. Rivas Velarde et al. (2018:1431), for example, emphasise how 'indigenous peoples are not included as a protected group within the binding text of the Convention, even though indigenous peoples are disproportionately represented among persons with disabilities worldwide'. These authors go on to observe how the CRPD mechanisms still need to understand the needs and priorities of indigenous people, and to provide for an articulation of these through an indigenous perspective, and which in turn requires 'a re-distribution of power, honouring indigenous sovereignty' while pushing for the 'abolishing of unilateral decision-making, limited participation and inefficient communication'. The CRPD, they categorically state, needs to be 'reconstructed with a language and discourse that makes sense of the needs and struggles of indigenous persons with disabilities'.

Findings from the interviews as well as reviews of the shadow reports and literature, highlight a population that remains at the fringes of awareness and knowledge, of planning and programming, reporting and importantly of self-representation. This indigenous Guatemalan person is categorical:

*Sincerely I have heard about it (CRPD), but I have not paid so much attention to what it means...if we speak about articles, they are many and difficult to analyze it and know in reality what it is telling us.*

**(Participant, Guatemala)**

This is a population that experiences the interaction between multiple forces including racism, geographical isolation, history, language barriers, political discrimination, and reduced access to critical services among others. Indigenous participants in the interviews explained how the CRPD was not even existent to most indigenous people, not least because it is not translated into indigenous languages, and the terminology used may not even be contextually relevant. Not knowing what is in it, implies a localization process that may be totally disconnected. Importantly, interviews demonstrated how indigenous people may well be more concerned about the most basic needs and survival, which means that discourses on rights, advocacy, and even localization of a policy or framework perceived to make no difference to their lives, are once again not seen as important. This rather lengthy quote by an indigenous participant in this study lays out many of these interwoven obstacles:

*The major barriers? From my experience...it is that I am an indigenous woman. Having a disability and being a woman, all of this limits, starting from...respecting my rights, I have been in spaces where I have always been discriminated against, because they believe I cannot speak Spanish for example. But yes I can, and I can also speak my language, which is Kaqchikel...and even in employment, I have been able to get some work, but it is only out of obligation and I am only paid something small, and it is not something that should be like this, because I want to apply for work, because I am educated enough for what I am looking for...but sincerely it is very difficult and I have seen that there is much difference between a man with a disability and a woman...I tell you this from my experience, because they paid him (a man) the minimum wage, but they paid me only something token and small and they put me to work in an area that I was overqualified to do. (Participant, Guatemala)*

### 3.2.12 Reporting and its limitations

The issue of reporting emerged at multiple points across the studies, once again highlighting interwoven barriers particularly bound to the expectations around reporting and the dynamics of how countries and stakeholders go about doing this. Some barriers were marked:

- Countries may often want to put a positive spin on things, so periodic and initial country reports frequently do not cover any areas that are lacking, which is where the actual focus should be. Instead, the nature and purpose of the reports submitted both by State parties and by non-state actors, provide a somewhat biased data base. Periodic reports from State parties focus on what has been achieved (usually primarily with regards to legislation and policies at national level) and generally avoid focusing on the challenges in implementing the Convention. Maintaining the status quo and political acquiescence take priority.
- Shadow reports, on the contrary, often focus almost entirely on gaps, so there is hardly any attention to positive changes and may not always be very propositional. This may act as a diplomatic fissure with governments that may be resistant to criticism.
- Many countries only report on legislation and plans and almost nothing on implementation at a local level
- Lack of consultation at local levels: developed at a national level, not much is known on the local level. This is reflected to some extent in the shadow reports where it is often national level OPDs and human rights institutions and CSOs that are developing these reports, but which are often not necessarily reporting on local issues.
- The process itself: often a state report will be submitted, civil society will examine the state report, and write a shadow report that then goes to the Committee which considers all reports regarding a particular State party.

However, these reports may not necessarily reflect broader civil society issues. Furthermore, because the CRPD has no legal standing, all the committee can do is provide recommendations, implying there is no way for a state party to be held to account apart from when a committee investigates a country. The only way is to take cases to court to develop legal precedent with regards to violations of the rights of persons with disabilities in a country. However, this is arduous and also costly, which means that without adequate funding and given that legal cases take such a long time, the plaintiff may run out of finances and therefore cases are dropped on their own accord.

## 4. Recommendations

This section pulls together a number of recommendations that can be drawn from the study. They are split into overarching and specific recommendations for ease of reading. They are not mutually exclusive, but instead are meant to complement each other.

### 4.1 Overarching recommendations

Develop a conceptualization of ‘localization’ of the CRPD that establishes this as a systemic approach in its own right.

We need to move away from a generalized discourse on local implementation towards ‘localization of the CRPD’ as an established term. The concept of localization in the implementation of the CRPD is largely understood as a top-down law implementation process as opposed to a holistic all-society involving and transformative process- where the international, national and local level need to be in a symbiotic and dynamic continuous cycle of action and feedback. Systemic localization of the CRPD requires a ‘whole of society’ approach and a transformation process in the way that international and national institutions, the private sector and citizens collaborate to achieve the goals of the framework. Additionally, effective and meaningful localization is more than just local implementation of the CRPD, but an ambitious and complex cycle and interplay of processes that include mechanisms from international to national and local and vice versa.

Further research into ‘localization’ and pilot studies are therefore urgently needed to clearly articulate a conceptualization that will guide a holistic implementation strategy across all levels, macro, meso and micro that are cognisant of geopolitics.

This can be accommodated through a chapter on localization in the new world report on disability, to emphasise its transversal importance.

Understand and implement the localization of the CRPD as an ongoing process

On one hand, a systemic and sustainable localization of the CRPD cannot be limited to integrating the global framework in national legislation and policies, but must extend to the strengthening of local knowledge and governance. This includes innovative methodologies to co-design and implement together with persons with disabilities, civil society and private actors, financing tools and mechanisms for accountability as well as legal enforceability. At the level of upstream policy making, national governments need to create the policy, legal and fiscal frameworks, coordination systems and institutions that can enable local stakeholders at all levels to operate, innovate and forge the necessary partnerships to make the CRPD real.

On the other hand, at a sub-national level, local stakeholders are critical in understanding local contexts and power asymmetries, creating the enabling conditions for multi-stakeholder engagement, and for translating the CRPD into an implementable framework.

Feedback mechanisms must be in place and maintained to ensure that local information, experiences, complaints and proposals, including locally generated data reach the relevant national and international bodies, such as the CRPD commission and the CRPD monitoring and reporting systems, which will in return, and ideally, feedback into and result in improved national and local policies and practices.

A genuinely holistic, dynamic, ongoing and responsive framing of localization needs to be developed that does not merely imply implementing a global framework that we assume somehow trickles-down from international to national to the local level. Instead, it means a cycle that is constantly being fed (and also at times interrupted) by multiple factors and processes within complex national, local and geopolitical ecosystems that are themselves consistently changing and dynamic.

Be alert and responsive to the context that influences the process of localization

The dynamics and hence the effectiveness of localization are embedded in and linked to the wider and diverse geographical, cultural, ideological, socio-economic, legal, and political ecosystem. There is a strong link between discrimination, disempowerment, poverty, and poor access to justice. Systemic barriers, such as extreme poverty, deeply entrenched stigma or wider discrimination based on race or ethnicity need to often be addressed first, to ensure access to justice as fundamental human right for all and that is essential for the protection of all other economic, social, cultural, and political rights.

## 4.2 Specific Recommendations

For global stakeholders (policymakers, monitoring bodies and academia)

- Advocate for and support the CRPD committee in issuing a General Comment on Article 33 (monitoring and implementation at the national level) which focuses on localization. In this regard, the concept of ‘localization’ can therefore be introduced and properly defined.
- Ensure that **reporting procedures to the CRPD** committee genuinely reflect local concerns, including issues of poverty and indigeneity, and not those of privileged stakeholders from privileged areas.
- **Sensitize UN country offices** on the CRPD.
- Push for **quality, disseminated local data** on disability.
- **Develop a two pronged practical tool** that a) supports countries to identify priority areas for localization and develop a comprehensive strategic plan for localization and b) supports existing structures and workforces in these countries (including the legal profession) to effectively localize the CRPD.

For governments (national and local)

- Ensure **there are more individuals at a political directorate level** who understand the CRPD and can effectively influence its implementation

- Ensure **local budget and funding** as critical components of localization are available.
- **Review national policy frameworks and laws in multiple areas** (e.g. justice and employment) so that these are informed by and responsive to the local needs of persons with disabilities.
- Ensure **access to justice is guaranteed** in all communities, including informed and sensitized legal professionals.
- Put in place structures for **disability focal persons in all local government** offices and ensure they are audited.
- **Work with OPDs** not as recipients of charity, but rather as participants **in the governance process**.

For Organizations of Persons with Disabilities (OPDs)

- Make sure that **OPDs are genuinely representative of all people with disabilities** especially those in marginalised rural areas and not only a select few.
- **Establish an active mentorship program for younger generations** of persons with disabilities to gain leadership positions in OPDs.
- Build **stronger networks and links to mainstream civil society organizations**.
- **Work actively against the fragmentation of the disability movement** by sharing experiences with each other, working towards common key goals and raising of funds together.

For mainstream civil society stakeholders

- **Strengthen community organisations** and ensure they exist in the first place.
- **Ensure that disability is solidly infused within other areas of practice**, and that voices from these other fields are heard and represented as genuine partners.
- **Include mainstream Civil Society Organizations in CRPD implementation**. Without this, disability will remain siloed.
- **Foster and facilitate partnerships with OPDs**, local and national and with disability advocacy groups.

## 5. References

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## ANNEX 1: ARTICLES ANALYZED IN SCOPING REVIEW OF ACADEMIC LITERATURE

Article title	Author(s)
Participation of people with disabilities in local governance: presentation of a project aimed at measuring the impact of inclusive local development strategies.	Normand, B; Pascale, V; Geiser, P. & Fougeyrollas, P.
Lives of persons with disabilities in Cameroon after CRPD: Voices of persons with disabilities in the Buea Municipality in Cameroon.	Opoku, P; Mprah, K; Mckenzie, J; Sakah, N & Badu, E.
Implementation of the 2006 Convention on the Rights of Persons with Disabilities in Zimbabwe: A review.	Dziva, C; Shoko, M & Zvobgo, E.
Implementing the United Nations Convention on the rights of persons with disabilities: principles, implications, practice and limitations.	Lang, R; Kett, M; Groce, N & Trani, J.F.
Domestication Of the Convention on The Rights of Persons with Disabilities (CRPD) at District level.	Guzu, B.
The Convention on the Rights of Persons with Disabilities and its implications for the health and wellbeing of indigenous peoples with disabilities: A comparison across Australia, Mexico and New Zealand.	Velarde, M; O' Brien ,P & Parmenter, R.
Trading autonomy for services: Perceptions of users and providers of services for disabled people in Iceland.	Love, L; Traustadóttir, R. & Rice, J.
United Nations Convention on the rights of persons with disabilities (UNCRPD) Implementation: Perspectives of persons with disabilities in Namibia.	Chibaya, G; Govender, P & Naidoo, D
Indigenous persons with disabilities and the convention on the rights of persons with disabilities: An identity without a home?	Harpur, P. & Stein, M. A.

Article title	Author(s)
The domestic incorporation of human rights law and the United Nations Convention on the Rights of Persons with Disabilities.	Lord, J. E. & Stein, M. A.
Prospects and practices for CRPD implementation in Africa.	Lord, J. & Stein, M. A.
Transposing the Convention on the Rights with Disability in Africa: The role of Disabled People's Organizations.	Mahomed, F; Lord, J E & Stein, M. A.
Community for all: Implementing article 19- A guide for monitoring progress on the implementation of article 19 of the Convention on the Rights of Persons with Disabilities.	Parker, C.

## ANNEX 2: UN REPORTS ANALYZED IN SCOPING REVIEW

COUNTRIES	PERIODIC REPORTS		CONCLUDING OBSERVATIONS		SHADOW REPORTS	
	No.	Dates	No.	Dates	No.	Dates
Algeria	-		1	2019		
Ethiopia	-		1	2016		
Gabon	-		1	2015		
Kenya	-		1	2015	3	2015
Malawi	1	2017	-			
Mauritius	1	2020	1	2015		
Morocco	-		1	2017		
Namibia	1	2020	-			
Nigeria	-		1	2019		
Rowanda	-		1	2019		
Senegal	-		1	2019		
Seychelles	-		1	2018		
South Africa	-		1	2018	4	2018
Sudan	-		1	2018		
Tunisia	1	2018	1	2011		
Uganda	-		1	2016		

COUNTRIES	PERIODIC REPORTS		CONCLUDING OBSERVATIONS		SHADOW REPORTS	
	No.	Dates	No.	Dates	No.	Dates
Asia						
Armenia	-		1	2017		
Azerbaijan	-	2021	1	2014		
China	1	2019	1	2012		
Hong Kong	1	2019	-			
India	-		1	2019		
Macao	1	2019	-			
Mongolia	1	2020	1	2015		
Myanmar	-		1	2019		
Nepal	-		1	2018		
Philippines	-		1	2018	4	2013/15/18
Republic of Korea	1	2019	1	2014		
Russian Federation	-		1	2016		
Thailand	1		1	2019		
Turkey	-		1	2015		
Turkmenistan						

COUNTRIES	PERIODIC REPORTS		CONCLUDING OBSERVATIONS		SHADOW REPORTS	
	No.	Dates	No.	Dates	No.	Dates
Albania	-		1	2019		
Austria	-		1	2013		
Belgium	-		1	2014		
Bosnia	-		1	2017		
Bulgaria	-		1	2018		
Croatia	1	2021	1	2015		
Cyprus	-		1	2017		
Czech Republic	-		1	2015		
Denmark	1	2020	1	2014		
Estonia	-		1	2021		
France	-		1	2021		
Germany	-		1	2015		
Greece	-		1	2019		
Hungary	1	2019	1	2022		
Italy	-		1	2016		
Latvia	-		1	2017		
Lithuania	1	2021	1	2016		
Luxembourg	-		1	2017		
Macedonia	-		1	2018		
Malta	-		1	2018		

COUNTRIES	PERIODIC REPORTS		CONCLUDING OBSERVATIONS		SHADOW REPORTS	
	No.	Dates	No.	Dates	No.	Dates
Europe						
Moldova	-	2020	1	2017		
Montenegro	-		1	2017		
Norway	-		1	2019		
Poland	-		1	2018		
Portugal	-		1	2016		
Serbia	-		1	2016		
Slovakia	1	2020	1	2016		
Slovenia	-		1	2018		
Spain	1	2018	1	2011, 2019		
Sweden	-		1	2014		
Switzerland	-		1	2022		
Ukraine	1	2020	1	2015		
United Kingdom	-		1	2017		

COUNTRIES	PERIODIC REPORTS		CONCLUDING OBSERVATIONS		SHADOW REPORTS	
	No.	Dates	No.	Dates	No.	Dates
Latin America & Carabean						
Argentina	1	2019	1	2012		
Bolivia	-		1	2016		
Brazil	-		1	2015		
Chile	-		1	2016		
Colombia	-		1	2016		
Costa Rica	-		1	2014		
Cuba	-		1	2019		
Dominican Republic	-		1	2015		
Ecuador	1	2019	1	2019		
El Salvador	1	2019	1	2019		
Guatemala	-		1	2016	5	2015, 2016
Haiti	-		1	2018		
Honduras	-		1	2017		
Jamaica	-		1	2022		
Nicaragua	2	2020, 2020	-			
Panama	-		1	2017		
Paraguay	-		1	2013		
Peru	1	2019	1	2012		
Uruguay	-		1	2016		

COUNTRIES	PERIODIC REPORTS		CONCLUDING OBSERVATIONS		SHADOW REPORTS	
	No.	Dates	No.	Dates	No.	Dates
<b>Middle East</b>	<b>No.</b>	<b>Dates</b>	<b>No.</b>	<b>Dates</b>	<b>No.</b>	<b>Dates</b>
Bahrain	1	2017	-			
Iran	-		1	2017		
Iraq	-		1	2019		
Jordan	-		1	2017		
Kuwait	.		1	2019		
Oman	-		1	2018		
Qatar	-		1	2015		
Saudi Arabia	-		1	2018		
United Arab Emirates	-		1	2016		
<b>Middle East</b>	<b>No.</b>	<b>Dates</b>	<b>No.</b>	<b>Dates</b>	<b>No.</b>	<b>Dates</b>
Canada	-		-	2017		
Mexico	1	2018	2	2014, 2022		
<b>Oceania</b>	<b>No.</b>	<b>Dates</b>	<b>No.</b>	<b>Dates</b>	<b>No.</b>	<b>Dates</b>
Australia	1		2	2013, 2019		
Cook Island	-	2019	1	2015		
New Zealand	1		1	2014		
Vanuatu	-	2019	1	2018		
<b>Total Report</b>	<b>28</b>		<b>95</b>		<b>17</b>	

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## **ANNEX 3: GUIDING QUESTIONS FOR SEMI-STRUCTURED INTERVIEWS**

- 1. What does the CRPD mean to you?**
- 2. What do you understand by “localisation” in relation to the CRPD?**
- 3. How is the CRPD relevant to your local context?**
- 4. How is CRPD relevant to persons with disabilities locally?**
- 5. To date, what has been the impact of the CRPD on the lives of persons with disabilities?**
- 6. How has the CRPD impacted on the lives of girls and women with disabilities?**
  - How has the CRPD impacted on the lives of persons with disabilities from ethnic minorities etc.?
- 7. How has the CRPD been relevant to families of persons with disabilities?**
- 8. To date, what changes in your community have you observed because of the CRPD?**
- 9. What are the roles (if any) of persons with disabilities in the local implementation of the CRPD?**
- 10. What roles should persons with disabilities play in the local implementation of CRPD?**
  - What are their priorities?
- 11. What are the roles (if any) of OPDs in the local implementation of the CRPD?**
  - What are their priorities?
- 12. Who in your context has the influence in your community that impacts the CRPD?**
- 13. What are the barriers to localisation of the CRPD in your context?**
- 14. What chances open up if there is more focus on implementing the CRPD in a contextualized way?**
- 15. What resources are needed to localise the CRPD effectively?**

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