



# Baseline Study

CBM Community Based Inclusive Development (CBID) Initiative

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## **EXECUTIVE SUMMARY**

Community Based Inclusive Development (CBID) is an approach to ensure that people with disabilities are respected and included in their communities on an equal basis in all areas of life. It is empowering people with disabilities to exercise their rights and gain greater control over their lives, while maximising community participation. It is based on the belief that the inclusion of marginalised people in development processes reduces poverty, builds community resilience, and benefits the whole of the community. CBID is a key element of CBM's multinational effort to create communities that are inclusive. In implementing the ideals of its projects CBM is guided by a CBID Initiative Plan spanning from 2020 to 2024.

### **Aims**

CBM commissioned the Including Disability in Education in Africa (IDEA) Research Unit in the Department of Health and Rehabilitation Sciences at the University of Cape Town (UCT), South Africa, to conduct the baseline study for the implementation of its CBID Initiative Plan. The current study focuses on collecting data (in 2020/2021) from 16 programmes across eight countries – Cameroon, Ethiopia, Honduras, India, Pakistan, Rwanda, Togo, and Zimbabwe –thereby establishing the baseline data for a longitudinal study on the effectiveness of CBID interventions of CBM's partner programmes in these countries and to extrapolate general learning for CBM's worldwide CBID programming.

The objectives of the current research were to:

- Reflect an accurate picture of the status quo in selected CBID programmes in eight countries in relation to the objectives provided in the CBM CBID Initiative Plan.
- Enrich an understanding of the communities in which CBM's project partners operate, including identifying problem areas in order to facilitate improvement in the implementation of CBID.
- Provide a baseline against which CBM's CBID work can be evaluated.

This report refers only to the 2021 baseline study. Follow-up data for longitudinal analysis will be collected in 2022 and 2024.



## Methodology

The intention of the study was that data from the 16 heterogeneous programmes would not be comparable across sites or countries, but rather aimed at establishing baselines to enable the monitoring of change over time. Interestingly, though, a number of issues raised by participants appeared across many locations, demonstrating a degree of commonality in the difficulties faced by the various local communities. At each of the 16 sites, the study collected data on indicators aligned to two of the four priority areas of the CBM CBID Initiative Plan:

- 1. Inclusive communities:** Communities are inclusive of all people with disabilities.
- 2. Inclusive systems:** Services and support systems are inclusive and functioning effectively in the community.

These priority areas were divided into sets of objectives, which were measured according to associated indicators. This report documents findings from two streams of data that address these priority areas:

- A **survey questionnaire** conducted with a sample of 30 persons with disabilities from each of the 16 programmes (Appendix A).
- **Focus group discussions** involving a range of stakeholders in the CBID programmes (one focus group discussion per programme).

According to the logic of the study, the survey data provided baseline measurement of the status quo regarding key objectives of the CBID Initiative Plan, while the focus group discussions aimed to elicit qualitative data that enriched this information and provided an understanding of the life circumstances of participants so as to inform improvements in project implementation. Participants were sampled on a voluntary basis from the 16 CBID programme sites, with two groups at each site: one participating in the survey (n=30) and the other in the focus group discussion (n=8–12).

Survey participants were people with disabilities who are part of the local CBID projects, while the focus groups aimed to include people with disabilities, community leaders, leaders of Organisations of Persons with Disabilities (OPDs),

parents of children with disabilities, and local project managers and staff. Data was collected between December 2020 and March 2021 in participants' home language. Survey data was collected using a mobile application developed for this purpose, while focus groups were held either online or face-to-face. Participation in the study was voluntary, participants were permitted to withdraw at any time, and confidentiality was ensured. All data gatherers were trained by IDEA.

## Findings

In total, 471 participants completed the survey across 16 programmes in eight countries. The target of 60 participants (30 from each of two local programmes) was attained in all countries except India (n=56) and Zimbabwe (n=55). The majority of survey participants were male (54.8%) and employed (58.2%). A minority reported living alone (9.8%) and less than half of the sample reported having completed secondary school (39.9%). The type of disability most reported was physical disability (69%), followed by visual impairment (17.6%), and this was the case for all countries. Sixteen focus group discussions were conducted (one per programme).

Following are the highlights of the survey (quantitative) and the focus group discussion (qualitative) data for each of the two priority areas. Each priority area has objectives that were measured in terms of sets of associated indicators.

### Priority Area 1: Inclusive communities

This priority area was assessed in terms of:

- **self-confidence** of persons with disabilities;
- **quality of support** available to persons with disabilities;
- **participation** of persons with disabilities in community activities;
- participation in **decision making** by persons with disabilities, including leadership roles; and
- communities being **respectful of rights** of persons with disabilities.

### **Self-confidence**

Only 18.9% of survey participants reported favourable levels of self-confidence. Data from focus group discussions highlighted that parents need support in raising children with disabilities who are confident about their rights. Further, education, sustainable livelihoods and a diminution of negative community attitudes were seen as central to growing self-confidence.

### **Quality of support**

Qualitative data highlighted the need for not just material, but also psychological support for people with disabilities. Educating the community on disability as an access and equity concern was seen as key to improving levels of support. There was also substantial emphasis on providing psychological, logistical and financial support, as well as training in disability care and equity issues, to families of persons with disabilities.

### **Participation**

Only a small minority of survey participants (19.5%) reported favourable levels of participation in community activities – a finding evident across many locations. Qualitative data revealed that people with disabilities were not always welcomed by community members and were sometimes stigmatised. Physical barriers, financial constraints, and inaccessible dissemination of information on community events also limited participation. The unwelcoming community environment appears to be both a cause and a consequence of the phenomenon of some parents hiding their children with disabilities from their communities. Discrimination was shown to cause shame and anguish in children with disabilities.

### **Decision making**

Representation of persons with disabilities in community leadership and decision-making roles was seen as extremely poor, and associated with negative community attitudes about their abilities. Internalised oppression among persons with disabilities, however, was also a concern. Stronger policies that demand representation, as well as the focused capacitation of potential leaders, was viewed as strategically important.

## **Respectful of rights**

Levels of discrimination reported in the survey data varied immensely, from a high of 93.3% in Cameroon, to lows of under 30% in India, Pakistan and Rwanda. However, the qualitative data reflected significant concern about discrimination across all countries, with the caveat that the local CBID programme had led to improvements in some areas. Negative stereotypes and responses of hatred or disgust were viewed as commonplace. Importantly, strong emphasis was placed on the painful reality of discrimination within families, as well as in institutions such as schools and places of work.

## **Priority Area 2: Inclusive systems**

This priority area was assessed in terms of access to healthcare, education, livelihoods, transportation, and housing.

### **Access to health care**

Only one-third of survey participants (34.2%) indicated good health, receiving the care they needed, and being treated with respect in health care settings, suggesting that, in a minority of areas, services may be inclusive and functioning. Despite this, only 19.1% of participants reported not accessing rehabilitation services when in need of them, which was often due to financial or transportation problems. Qualitative data showed how physical, attitudinal and financial barriers to accessing health care are commonplace, although improvements are noted in some countries and attributed to the work of CBID programmes. Disturbingly, some parents were known to avoid taking their children with disabilities to health care appointments, due to the fear of stigmatisation.

### **Access to education**

Qualitative data suggested that inadequate teacher training is a cause for widespread exclusion and discrimination experienced by children with disabilities in the education sphere. The situation is worsened by inaccessible built environments and the prohibitive cost of transportation. Children may also be excluded as a result of shame and ambivalence felt by parents.



### **Access to livelihoods**

According to focus group participants, issues with access to sustainable livelihoods were associated with exclusion from education and workplace discrimination.

### **Access to transportation**

Access to this key resource was viewed as poor in all countries, as reflected in the qualitative data. Contributing factors include discriminatory attitudes and financial barriers.

### **Access to housing**

While access to housing was regarded as problematic in some countries, further data is required to clarify this concern.

### **Summary**

- The data reflects some common issues for persons with disabilities in the participating CBID programmes, particularly around discrimination, access to services, lack of participation in community activities and decision-making processes at community level, as well as poor representation of persons with disabilities in leadership roles.
- There is substantial divergence in the data across countries and between programmes in a single country.
- The diverse outcomes indicate the need to address these programmatic issues and approaches in a targeted way, depending on the local context.
- The findings provide insight into the inherent interrelatedness between areas such as education, health, and livelihoods.
- It is recommended that, in the subsequent phases of this longitudinal study (2022 and 2024), analysis must be directed at how and to what effect multi-scale and interconnected areas in inclusive community development interact and connect.
- There are indications in the baseline data that community stakeholders in some places attribute improvements in some areas, such as stigma prevention and community awareness, to the work of the local CBID programme.

## INTRODUCTION

Over the past four decades, Community Based Inclusive Development (CBID) has grown from a single-sector (health) approach to a multisectoral approach implemented in over 90 countries around the world, predominately in low- and middle-income countries. Empowerment is at the heart of CBID and includes enabling people with disabilities to exercise their rights and have control of their lives. Promoted by the International Labour Organization (ILO), the United Nations Educational, Scientific and Cultural Organization (UNESCO) and the World Health Organization (WHO), CBID has become a discursive and practice approach intended to maximise the participation and inclusion of people with disabilities in their communities.<sup>1</sup>

CBID practice focuses on the creation of inclusive societies where people with disabilities have access to social and development benefits like everyone else in their communities. The rationale is that no-one should be excluded from development for any reason, and that the inclusion of marginalised people in development processes reduces poverty, builds community resilience, and benefits the whole community.

CBID is central to the implementation of the aims of CBM programming, accounting for more than 40% of the organisation's programmatic activity. As an approach to ensure that people with disabilities are respected and included in their communities on an equal basis in all areas of life, CBID is an essential contribution to CBM's vision of an inclusive world in which all persons with disabilities enjoy their human rights and achieve their full potential. Consequently, it is a key element in the implementation of CBM's strategy, and a practical expression of CBM's effort to address the broad issue of creating inclusive communities.

CBM CBID is working with diverse local development partners in several countries, all using CBID as their framework for implementation. In implementing the ideals of their projects, CBM is guided by a CBID Initiative Plan. This plan outlines the approach to programme implementation with local partners for the period 2020 to 2024.

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<sup>1</sup> ILO, UNESCO, WHO: CBR Joint Position Paper (2004).

## **Background and aims**

CBM commissioned the Including Disability in Education in Africa (IDEA) Research Unit in the Department of Health and Rehabilitation Sciences at the University of Cape Town (UCT), South Africa, to conduct the baseline study for the implementation of its CBID Initiative Plan. The current study focuses on collecting data (in 2020/2021) from 16 programmes across eight countries – Cameroon, Ethiopia, Honduras, India, Pakistan, Rwanda, Togo, and Zimbabwe – thereby establishing the baseline data for a longitudinal study on the effectiveness of CBID interventions of CBM’s partner programmes in these countries.

The objectives of the current research were to:

- Reflect an accurate picture of the status quo in selected CBID programmes in eight countries in relation to the objectives provided in the CBM CBID Initiative Plan.
- Enrich an understanding of the communities in which CBM’s project partners operate, including identifying problem areas in order to facilitate improvement in the implementation of CBID.
- Provide a baseline against which the work of CBM CBID can be evaluated.

Primarily, the study’s findings aimed to track longitudinal changes in the baseline areas of study, while also providing qualitative data to enrich understanding of issues in programme implementation.

This report refers only to the 2021 baseline study involving data collection between December 2020 and March 2021, which will provide an information base against which the following two phases will assess the progress and effectiveness of the implementation of the CBM CBID Initiative Plan. Follow-up data for longitudinal analysis will be collected in 2022 and 2024.

The list of 16 participating programmes identified below were chosen by CBM regional offices, primarily because they were seen as feasible during the COVID-19 pandemic and were representative of CBID work:

**Table 1:** Participating countries and programmes.

Country	Programme
<b>Cameroon</b>	<ul style="list-style-type: none"><li>• Projet d'Appui à la Promotion des Personnes Handicapées de la région du Centre-Cameroun</li><li>• Enhancing Capabilities and Participation of Persons with Disabilities in the North West and Clubfoot Care in Cameroon</li></ul>
<b>Ethiopia</b>	<ul style="list-style-type: none"><li>• Bridge the GAP: CBID Project in East Gojjam implemented by BFI</li><li>• Jimma-Illubabor CBR Project, implemented by CFAI</li></ul>
<b>Honduras</b>	<ul style="list-style-type: none"><li>• Project 815 Desarrollo Económico Inclusivo y Sostenible para poblaciones vulnerables con énfasis en personas con discapacidad, mujeres y pueblos indígenas en Honduras (CUSO)</li><li>• Project 815 Honduras Inclusiva (PREPACE)</li></ul>
<b>India</b>	<ul style="list-style-type: none"><li>• Naman Seva Samiti (NSS), Madhya Pradesh</li><li>• Project 204 Anchalik Samrudhi Sadhana Anusthan (ASSA), Odisha</li></ul>
<b>Pakistan</b>	<ul style="list-style-type: none"><li>• Bedari</li><li>• Doaba Foundation</li></ul>
<b>Rwanda</b>	<ul style="list-style-type: none"><li>• GRC CBID/Livelihood in Kayonza</li><li>• HVP Gatagara/Gikondo School</li></ul>
<b>Togo</b>	<ul style="list-style-type: none"><li>• Communauté Partenaire pour le Développement Inclusif (CPDI)</li><li>• Femme Handicapée en Action pour le Développement Inclusif au Togo (FHAIT)</li></ul>
<b>Zimbabwe</b>	<ul style="list-style-type: none"><li>• Inclusive Education</li><li>• Bulawayo Urban CBR</li></ul>

## METHODOLOGY

This baseline study was implemented across 16 diverse CBID programmes in eight countries. The intention was that data from these 16 heterogeneous programmes would not be comparable across sites or countries, but rather aimed at establishing baselines to enable the monitoring of change over time.

Effectiveness was defined in relation to the CBM CBID Initiative Plan, which sets out the following desired outcomes or priority areas:

**1. Inclusive communities:** Communities are inclusive of all people with disabilities.

**2. Inclusive systems:** Services and support systems are inclusive and functioning effectively in the community.

**3. Disaster prepared communities:** Communities are resilient and disaster prepared.

**4. Thought leadership and influence:** CBM is established as a global thought leader in CBID.

The four strategic priority areas were developed with associated objectives and indicators. In this report, we document findings for priority areas 1 and 2, which were assessed at baseline (to be followed up later), for the 16 programmes across the eight countries. The pre-identified objectives and indicators of the CBM CBID Initiative Plan are indicated in Table 2.

**Table 2:** Baseline study priority areas, objectives, and indicators.

<b>Priority Areas</b>	<b>Objectives</b>	<b>Indicators (measurements of success)</b>
<b>1. Inclusive Communities</b> Communities are inclusive of all people with disabilities.	<b>A.</b> Persons with disabilities and their families have the capacities, support and confidence to participate in community life.	<b>1.</b> Self-confidence of people with disabilities increases measurably on a qualitative scale. <b>2.</b> Women, men, girls and boys with disabilities and their families report improved quality support available to them. <b>3.</b> Increased participation of people with disabilities in selected community activities.
	<b>B.</b> Communities use their resources and networks and mobilise to ensure participation of people with disabilities.	<b>1.</b> Number of persons with disabilities who actively participate in decision-making processes at community level. <b>2.</b> Community members are respectful of the rights of persons with disabilities.
<b>2. Inclusive systems</b> Services and support systems are inclusive and functioning effectively in the community.	<b>A.</b> Mainstream and individual disability-specific services are of good quality, accessible, available, affordable, and accepted by all at community level.	<b>1.</b> Increased number of persons with disabilities accessing local services. <b>2.</b> Increased number of assistive devices provided. <b>3.</b> A multisectoral network of service providers is available to the community.

The evaluation study drew on three data streams:

1. A **survey questionnaire** conducted with a sample of 30 persons with disabilities from each programme (Appendix A).
2. **Focus group discussions** (one per programme) involving programme participants, parents of children with disabilities, leaders of Organisations of Persons with Disabilities (OPDs), community leaders, and local programme managers and staff.
3. **Desktop research**, drawing on records and information in the public domain, such as public policies.

This report deals with the data streams from the survey questionnaire and the focus group discussions in the initial 2020/2021 data-collection phase.

## **Population and sample**

The population for this study were participants in 16 selected CBID programmes. The programmes were selected by convenience sampling. There were two sample groups at each site: one participated in the completion of the survey and the other participated in the focus group discussions. The sampling for the evaluation survey was non-randomised and relied on volunteers from each programme. Purposive sampling was performed to form the focus groups, made up of 8–12 participants at each site.

## **Recruitment for the survey**

The CBM partner in each country used its project records to identify persons with disabilities and invited them to take part in the study. Participants were provided with information about the project in their home language. There was no obligation to take part in the evaluation and potential volunteers were able to withdraw at any time.

## **Inclusion criteria**

The criteria for inclusion in the survey were:

- Persons with a disability who are part of the local programme.



- Persons who are between the ages of 18 and 65.
- Persons who are able to communicate in the local language.
- Persons who are able to provide informed consent.

### **Recruitment of focus groups**

One focus group discussion per programme was performed, bringing together stakeholders comprising persons with disabilities, community leaders, leaders of OPDs, parents of children with disabilities, and local project managers and staff through purposive sampling by the CBM partner. They identified relevant stakeholders from their projects and invited them to participate, ensuring informed consent was obtained and confidentiality maintained.

### **Data collection**

Data was collected across the 16 programmes over a period of three months, from December 2020 to March 2021. Surveys and focus group discussions were conducted in participants' home language to ensure accessibility. The translation of questionnaires and focus group discussion schedules was performed by CBM staff in each country. This translation process was thorough and involved back translation in each language. Because of the COVID-19 pandemic, methodologies were adapted to ensure the safety of participants.

### **Survey**

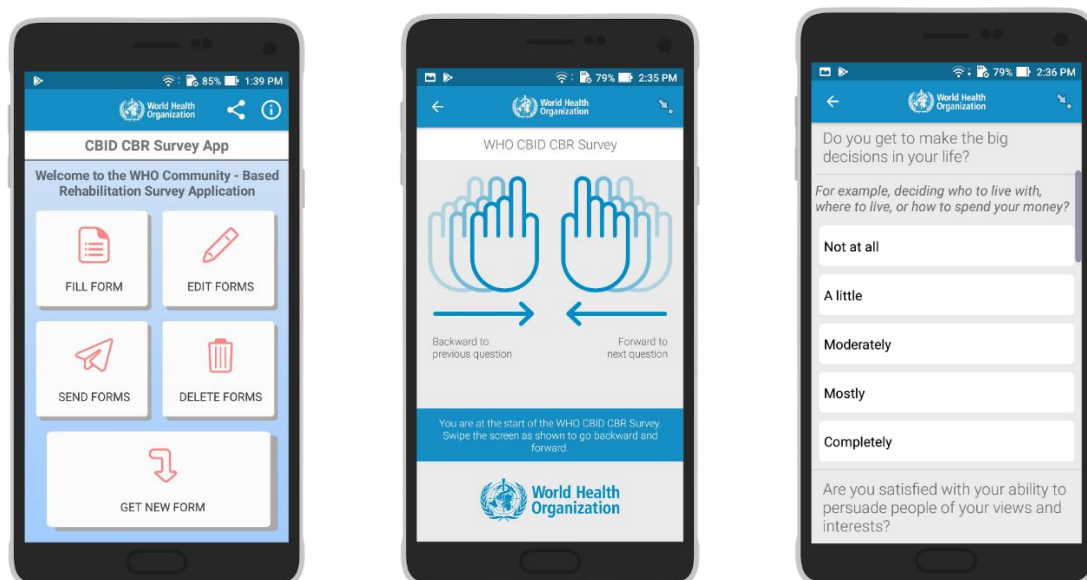
The survey data was collected through a mobile application (Appendix A) by data gatherers trained by IDEA. The advantage of using a mobile application was that data could be monitored and managed in real time, while ensuring consistency across countries and minimising human error in data entry.

The CBID CBR App was created in close collaboration by CBM, UCT and UniversalDoctor. It is based on the WHO CBR Survey App, which was developed by UniversalDoctor for the WHO Department for Management of Noncommunicable Diseases, Disability, Violence and Injury Prevention (NVI) in order to facilitate mobile data collection on community-based rehabilitation (CBR) indicators. These indicators are capable of capturing the difference CBR makes in the lives of persons with disabilities who live in communities where CBR is

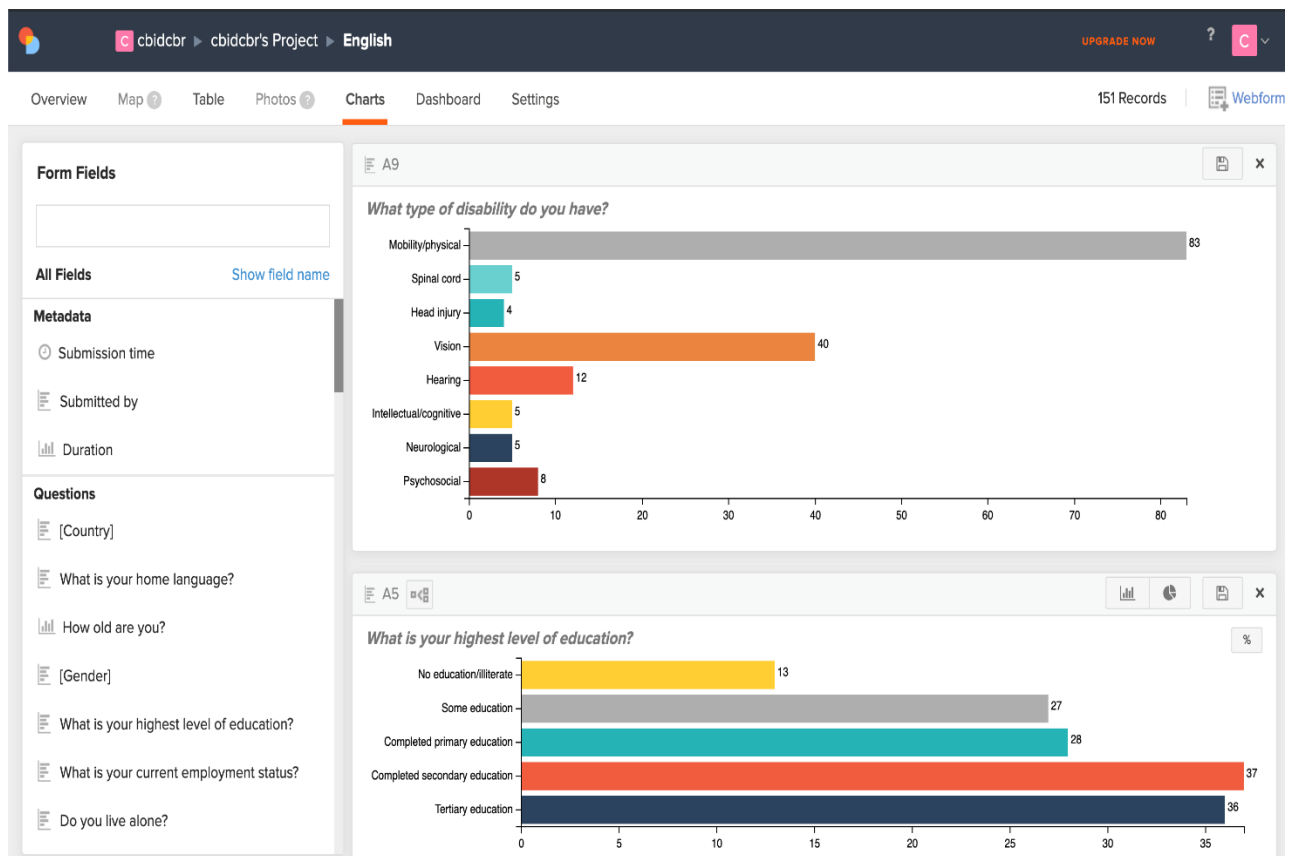
implemented. This tool was adapted specifically to the requirements of the CBID baseline study.

UniversalDoctor deployed the CBID CBR surveys through a native Android application, the CBID CBR App, as well as web-based forms accessible via a browser on any device, allowing data collection from mobile devices, PCs or tablets. The CBID CBR App is a customised version of the original mobile data-collection tool that uses Open Data Kit (ODK) technology to enable easy, offline and multilingual data-collection on mobile devices in remote areas. The App incorporates custom skip logic to facilitate the completion of the surveys and avoid data entry errors. Once collected on the mobile device, the data could be saved offline locally to the device and submitted to the database whenever Internet connectivity was available via a secure server connection.

The final data sets containing the submissions from the App used at each field site was managed through a web-based data dashboard called Ona Data, which stored the data collected and offered real-time monitoring of data submissions from the App. The dashboard enabled the visualisation and sharing of data as it was collected, and to export it in different formats for more advanced analysis.



**Figure 1:** Screens from the CBID CBR mobile application that surveyors used to collect data, both online and offline, for the baseline study. The mobile application is based on the WHO CBR Survey App, which was customised for the CBID study.



**Figure 2:** Data collected via the CBID CBR App were submitted by the surveyors in the different countries to the data dashboard. This data was accessed in real time by the data analysis team to visualise, export and analyse the data.

## Focus groups

The focus group data was collected either on an online platform or in person. Each discussion took between 60 and 90 minutes. The interviews were conducted by data gatherers trained by IDEA. The focus group schedule (Appendix B) aimed to elicit qualitative data that addressed aspects of the CBM CBID project goals that could not be addressed in depth by survey data. It also sought to provide an enriched understanding of the life circumstances of participants, as measured in the survey data, to inform improvements in the implementation of the CBM CBID Initiative Plan.

## **ETHICAL PRINCIPLES**

The World Medical Association's Declaration of Helsinki (1964) is a set of ethical principles relating to experimentation and research involving human subjects. The general ethical guidelines embody the ideals to which the team conducting this research aspire and subscribe. Article 8 speaks to the fundamental principle of respect for the individual, while Articles 20, 21 and 22 relate to the right of participants to make informed decisions about participating in research, both prior to and during the course of the research process. The researcher's duty must be solely to the participant (Articles 2, 3 and 10) or research volunteers (Articles 16 and 18). Article 5 of the Declaration acknowledges that, while research is essential, the participant's welfare must always take precedence over the interests of science and society. Article 9 states that ethical considerations must always take precedence over laws and regulations.

It is noteworthy that participants in this study include persons with disabilities, who can be seen as individuals needing special vigilance (Article 8) as they are at risk of increased vulnerability. The researchers were aware of this and implemented the necessary precautions and modifications to the method.

### **Informed consent**

The researchers in this study:

- Gave research participants full information about the nature and effect of the research – in particular the effect of the research on the participants, including its consequences, risks, and benefits – to enable them to make an informed choice about their participation.
- Recognised that responsibility for the well-being of research participants always rests with the health researcher – not the research participants – even though the latter have given consent.
- Gave information to research participants in a language that the participant understood, and in a manner that took into account the participant's level of literacy, understanding, values, and personal belief systems.
- Ensured at all times that participation was voluntary and not coerced.

- Refrained from purposefully withholding from research participants any information, investigation or procedure that health-care practitioners knew was in the best interests of the participants.
- Ensured that the research participant understood the information before obtaining the participant's freely given informed consent. If the consent could not be obtained in writing, non-written consent was fully documented and witnessed. Verbal and written informed consent were obtained unless there were good reasons for not doing so (Appendix C and D).

### **Confidentiality**

The researchers in this study ensured that none of the participants' personal information was shared with any other party.

### **Ethical clearance**

Ethical clearance was obtained from the University of Cape Town, Faculty of Health Sciences, Human Research Ethics Committee: HREC REF: 676/2020.

## **LIMITATIONS TO THE BASELINE STUDY**

Like any other study, this baseline has some limitations and caveats. The current study focused on collecting baseline data on selected objectives of the CBM CBID Initiative Plan from 16 CBM supported CBID programmes across eight countries, all with diverse background and goals in inclusive development. The main aim of this baseline study was not to provide a generalisable picture of the disability experience in these countries, but to:

- Capture the current situation with regards to specific indicators across these CBID projects, collate baseline data and ensure that this data can be updated in the longer term.
- Ensure that the baseline data can be replicated during ongoing activity monitoring.

- Provide an information base for monitoring and assessing the activities of the CBM CBID Initiative Plan and the effectiveness of the programmes' interventions.
- Provide data to inform and motivate the CBM and the local programme stakeholders to pay attention to certain issues and increase their participation.
- Provide justification to policy makers and donors for a project intervention.
- Shape expectations and communication strategies.

The 16 programmes that volunteered to participate in this study were selected because of their geographic, cultural, and technical diversity and accessibility. However, this implies that the outcomes of the data collection cannot be compared between countries. Therefore, this baseline study cannot claim to represent a generalised picture of inclusive community development that attributes all change to CBM in the countries involved or globally. It is rather a snapshot of the complexity of disability experience in selected communities. The next waves of this longitudinal study (planned for 2022 and 2024) will give a more in-depth understanding of the indicators measured in the communities and programmes involved, and possibly allow the identification of local trends and actionable insights.

The data collection for this baseline study was conducted during the height of the COVID-19 pandemic. Social-distancing protocols, shelter-in-place orders and travel restrictions across the globe posed unique challenges to research activities, often grounded by the researchers' physical presence in communities. Although technology can facilitate virtual data collection (i.e. phone calls, video conferences), the inability to conduct in-person research in most countries may have disproportionately affected access to geographically isolated or disadvantaged populations. The sampling for this study therefore relied on the accessibility of participants (via phone or in a safe location), which might have excluded some people who have been severely impacted by the pandemic or are living in less accessible locations.

Limited in-person fieldwork may also create barriers to gaining access and building trust with communities. IDEA tried to mitigate this by selecting data collectors



who were not new to the communities and had community partners or key informants.

In addition to the challenges of gaining access to disadvantaged communities, it may also be difficult to establish rapport with individual participants during interviews via phone. This is especially a concern if personal issues are discussed. During IDEA's training sessions with the data collectors, they were explicitly prepared to set the interviewees at ease by granting them sufficient space for responses and providing encouragement. Additionally, the IDEA research team was in constant contact with the field researchers, reacting to and proposing recommendations to the challenges posed by the pandemic to the research process, which included in some instances postponing data collection.

The baseline study was conducted in 10 local languages. Although strict research protocols in translation procedures were followed, there is the possibility that meaning is lost in translation, alongside the nuances of language, including localised words and expressions that do not exist in English or are not easily translated. The research team endeavoured to translate and present quotes in ways that reflect some of the nuances and even idiosyncrasies of language and its use.

## **RESULTS OF THE BASELINE STUDY**

This section presents the survey and focus group data from the baseline phase (2020/2021) of the project. The quantitative survey data set is presented in a way that aligns with the indicators of the CBM CBID Initiative Plan and is followed by corresponding data from the focus groups. Only statistically relevant results of the quantitative data are referred to in the accompanying narrative.

To establish the baseline, quantitative and qualitative data sets were not integrated at this point. From the next phase of the longitudinal design (2022) a convergent design will be used to compare and validate findings, and qualitative data will be employed to augment quantitative outcomes.

## Survey sample demographics

In total, 471 participants were interviewed in eight countries: Cameroon, Ethiopia, Honduras, India, Pakistan, Rwanda, Togo, and Zimbabwe. The target sample of 60 participants was reached in all countries except India (n=56) and Zimbabwe (n=55). Overall and country-specific demographic characteristics of the sample are presented in Table 3 and Table 4 respectively. The majority of participants were male (n=258, 54.8%) and employed (n=274, 58.2%). A minority reported living alone (n=46, 9.8%) and less than half of the sample reported having completed secondary school (n=188, 39.9%). The type of disability most reported was physical disability (n=325, 69%), followed by visual impairment (n=83, 17.6%), and this was the case for all countries. As expected, the participants' demographic characteristics varied greatly by country.

**Table 3:** Overall socio-demographics and disability characteristics of the survey sample (n=471)

	N	%
Female	213	45.2
Completed secondary school	188	39.9
Employed	274	58.2
Lives alone	46	9.8
Lives with spouse/children <sup>a</sup>	232	54.6
<i>Type of disability/impairment</i>		
Mobility/physical	325	69.0
Spinal cord injury	30	6.4
Head injury	5	1.1
Vision	83	17.6
Hearing	18	3.8
Intellectual/cognitive	27	5.7
Neurological	34	7.2
Psychosocial	2	0.4
	Mean	SD
Age	39.1	13.66
Total number of disability type	1.1	0.35

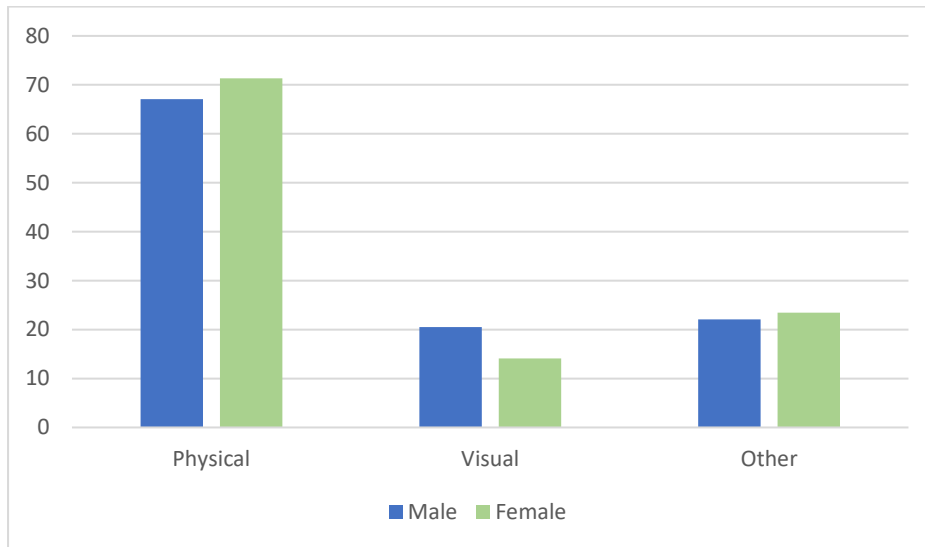
<sup>a</sup> Among those not living alone

**Table 4:** Socio-demographics and disability characteristics by country.

	Cameroon (n=60)		Ethiopia (n=60)		Honduras (n=60)		India (n=56)		Pakistan (n=60)		Rwanda (n=60)		Togo (n=60)		Zimbabwe (n=55)	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Female	25	41.7	19	31.7	27	45.0	10	17.9	32	53.3	26	43.3	47	78.3	27	49.1
Completed secondary school	32	53.3	29	48.3	18	30.0	27	48.2	26	43.3	14	23.3	8	13.3	34	61.8
Employed	30	50.0	41	68.3	24	40.0	39	69.6	38	63.3	27	45.0	40	66.7	35	63.6
Lives alone	16	26.7	8	13.3	3	5.0	0	0	0	0	9	15.0	4	6.7	6	10.9
Lives with spouse/children <sup>a</sup>	19	43.2	41	78.8	22	38.6	22	39.3	37	61.7	21	41.2	39	69.6	31	63.3
<i>Type of disability/impairment</i>																
Mobility/physical	36	60.0	44	73.3	37	61.7	30	53.6	47	78.3	43	71.7	50	83.3	38	69.1
Spinal cord injury	0	0	3	5.0	3	5.0	1	1.8	3	5.0	10	16.7	1	1.7	9	16.4
Head injury	0	0	2	3.3	0	0	0	0	1	1.7	1	1.7	0	0	1	1.8
Vision	24	40.0	12	20.0	6	10.0	9	16.1	9	15.0	0	0	8	13.3	15	27.3
Hearing	2	3.3	2	3.3	3	5.0	5	8.9	1	1.7	0	0	0	0	5	9.1
Intellectual/cognitive	0	0	2	3.3	8	13.3	9	16.1	2	3.3	2	3.3	3	5.0	1	1.8
Neurological	0	0	4	6.7	4	6.7	4	7.1	4	6.7	18	30.0	0	0	0	0
Psychosocial	0	0	0	0	1	1.7	0	0	0	0	0	0	1	1.7	0	0
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Age	37.1	13.46	38.1	11.15	40.80	16.72	33.5	12.16	36.4	14.29	36.9	12.86	45.8	10.56	43.9	13.50
Total number of disability type	1.0	0.18	1.1	0.48	1.0	0.18	1.0	0.19	1.1	0.37	1.2	0.46	1.1	0.22	1.3	0.48

<sup>a</sup> Among those not living alone

The type of disability most reported was physical disability (n=325, 69%), followed by visual impairment (n=83, 17.6%), and this was the case for all countries. A greater proportion of male participants reported visual impairment (n=53, 20.5%) compared to female participants (n=30, 14.1%; OR=1.58, p=0.067). No other gender differences were noted in relation to type of disability (Figure 3). As expected, the participants' demographic characteristics varied greatly by country (Table 4).



**Figure 3:** *Proportion of male and female participants reporting physical, visual and other impairments across countries.*



Priority Area 1  
Inclusive communities

For **Priority Area 1: Inclusive communities**, assessments were made of how closely communities approximated the ideal:

*Communities are inclusive of all people with disabilities.*

Below is a summary of Priority Area 1 objectives and indicators, followed by an outline of the research findings by indicator.

<b>Priority Area 1: Inclusive Communities</b>	
Communities are inclusive of all people with disabilities	
<b>Objectives</b>	<b>Indicators</b>
<b>A.</b> Persons with disabilities and their families have the capacities, support and confidence to participate in community life	<b>1.</b> Self -confidence of people with disabilities increases measurably on a qualitative scale <b>2.</b> Women, men, girls and boys with disabilities and their families report improved quality support available to them <b>3.</b> Increased participation of people with disabilities in selected community activities
<b>B.</b> Communities use their resources and networks and mobilise to ensure participation of people with disabilities	<b>1.</b> Number of persons with disabilities who actively participate in decision-making processes at community level <b>2.</b> Community members are respectful of the rights of persons with disabilities

## OBJECTIVE 1.A

**Persons with disabilities and their families have the capacities, support and confidence to participate in community life**

The level of inclusivity within communities was assessed by adding all responses in each of the five subscales. Scores for each subscale range from 0 (no inclusivity) to 24 (total inclusivity), depending on the number questions in each subscale: self-confidence (range of possible scores: 0–20), quality support (0–24), participation (0–8), decision-making (0–9), and respectful of rights (0–1). A higher score means greater inclusivity. Results are reported in Table 5 for each country and project.



**Table 5:** Level of inclusivity within the community by country and project.  
(Greater scores mean greater confidence/support/participation, etc.; SD=standard deviation)

	<b>CAMEROON</b>					
	All		Project d'Appui		Enhancing Capabilities	
	Mean	SD	Mean	SD	Mean	SD
Self-confidence (0–20)	11.8	4.18	13.0	3.85	10.5	4.17
Quality support (0–24)	12.8	2.29	12.8	2.05	12.8	2.56
Participation (0–8)	3.8	1.56	3.8	1.37	3.8	1.76
Decision-making process (0–9)	3.4	1.83	3.9	2.08	3.0	1.43
Respectful of rights (0–1)	0	0.18	0	0.00	0.1	0.25
	<b>ETHIOPIA</b>					
	All		Bridge the GAP		Jimma-Illubabor	
	Mean	SD	Mean	SD	Mean	SD
Self-confidence (0–20)	13.2	3.23	13.8	3.47	12.6	2.90
Quality support (0–24)	17.4	2.64	17.2	3.39	17.6	1.61
Participation (0–8)	3.3	1.28	3.4	1.43	3.2	1.13
Decision-making process (0–9)	3.5	1.38	3.1	1.42	3.8	1.26
Respectful of rights (0–1)	0.3	0.45	0.3	0.45	0.3	0.45
	<b>HONDURAS</b>					
	All		Desarrollo Económico		Honduras Inclusiva	
	Mean	SD	Mean	SD	Mean	SD
Self-confidence (0–20)	13.6	4.89	14.7	4.44	12.4	5.11
Quality support (0–24)	12.9	4.33	12.2	4.39	13.7	4.20
Participation (0–8)	2.3	2.03	2.3	2.05	2.3	2.04
Decision-making process (0–9)	4.6	1.80	5.4	1.79	3.9	1.50
Respectful of rights (0–1)	0.3	0.45	0.3	0.45	0.3	0.47
	<b>INDIA</b>					
	All		NSS		ASSA	
	Mean	SD	Mean	SD	Mean	SD
Self-confidence (0–20)	13.2	5.44	11.8	7.33	14.4	2.54
Quality support (0–24)	7.2	6.65	10.8	7.23	4.1	4.14
Participation (0–8)	5.6	2.48	4.8	2.62	6.3	2.15
Decision-making process (0–9)	5.6	2.49	4.0	2.53	7.0	1.39
Respectful of rights (0–1)	0.9	0.35	0.7	0.47	1.0	0
	<b>PAKISTAN</b>					
	All		Bedari		Doaba Foundation	
	Mean	SD	Mean	SD	Mean	SD
Self-confidence (0–20)	11.9	4.64	9.6	4.68	14.1	3.42
Quality support (0–24)	5.4	5.70	6.2	6.56	4.6	4.67
Participation (0–8)	3.0	1.92	2.2	1.91	3.7	1.67
Decision-making process (0–9)	4.8	1.88	4.0	1.84	5.7	1.54
Respectful of rights (0–1)	0.8	0.43	0.8	0.41	0.7	0.45

RWANDA						
	All		GRC CBID		HVP Gatagara	
Self-confidence (0–20)	11.9	4.76	11.2	4.88	12.6	4.60
Quality support (0–24)	10.4	4.39	10.8	5.31	10.0	3.28
Participation (0–8)	1.6	1.17	1.5	1.22	1.7	1.11
Decision-making process (0–9)	3.2	1.60	3.1	1.57	3.2	1.65
Respectful of rights (0–1)	0.9	0.36	0.8	0.38	0.9	0.35
TOGO						
	All		Communauté Partenaire		Femme Handicapée en Action	
Self-confidence (0–20)	14.8	4.97	18.3	2.46	11.4	4.43
Quality support (0–24)	4.4	5.07	1.9	3.44	7.0	5.21
Participation (0–8)	4.6	2.63	6.6	1.40	2.6	1.92
Decision-making process (0–9)	4.5	2.75	6.6	1.48	2.4	2.08
Respectful of rights (0–1)	0.7	0.48	1.0	0.00	0.3	0.48
ZIMBABWE						
	All		Bulawayo Urban		Inclusive Education	
Self-confidence (0–20)	14.3	4.52	14.3	4.31	14.3	4.80
Quality support (0–24)	13.0	7.11	12.8	7.12	13.1	7.23
Participation (0–8)	3.5	2.74	2.8	2.67	4.3	2.67
Decision-making process (0–9)	4.9	2.43	5.0	2.46	4.9	2.44
Respectful of rights (0–1)	0.5	0.50	0.4	0.50	0.6	0.50

Responses on the subscales were also dichotomised to identify participants endorsing each type of inclusivity indicator.

**INDICATOR**  
1.A1

**Self-confidence of people with disabilities increases measurably on a qualitative scale**

■ Cameroon

The Cameroon focus group discussion highlighted four issues that need to be addressed in order for persons with disabilities to have more control in their lives: building confidence through encouragement, improved access to education, availability of employment, and more involvement in community and day-to-day activities.

## ■ Ethiopia

The first, urgent issue to be raised by the Ethiopian group in connection with self-confidence was community attitudes. One participant began by stating:

*First of all, the attitude of the community should be changed. (Site 1, OPD)*

Government was named as, in part, responsible for mobilising such change. One participant elaborated powerfully:

*The negative attitude of the community make to develop the inferiority complex. We accepted what others saying about us and started to act accordingly. When the community says 'the person with disability is the cursed one', we accepted it and convinced ourselves as if we are the cursed ones. (Site 1, OPD)*

Further issues raised by this group in relation to building self-confidence were access to education and the ongoing problem of discrimination:

*If they stop these discriminations and support persons with disabilities, they will have more control over their life; they can become self-reliant, being free from dependency. (Site 2, OPD)*

## ■ Honduras

The discussion about building the self-confidence of persons with disabilities began with the need to give more support to parents:

*Here in my community what is needed is psychological help, because parents do not know how to act and isolate their children so that they are not exposed to ridicule from people. In my community there is medical help, inclusion; there are ramps in the social centre, in the mayor's office, in the church, in the school. The problem is the parent who does not take his child out; they overprotect him. (Site 1, Community Leader)*

Interestingly, this participant noted that addressing physical barriers is insufficient, and that building self-confidence requires change in how persons with disabilities are related to. Raising awareness of exclusion and ensuring greater opportunities for community involvement were also regarded as pivotal to giving persons with disabilities a greater sense of control in their lives.

## ■ India

In the focus group discussions, the central issues regarded as impacting on the self-confidence of persons with disabilities were the challenge of skills development and the need for financial support.

## ■ Pakistan

The question of sustainable livelihoods was viewed as central to the growth of self-confidence among persons with disabilities. With particular reference to the circumstances of women, one participant commented:

*Enhance livelihoods of women for their empowerment. Make them skilful. They may develop their businesses so that they may not become burden on others. (Site 1, OPD)*

## ■ Rwanda

Participants believed that education and awareness of rights play a key role in promoting a sense of control:

*There is a need for strong advocacy so that persons with disability can afford education and have a say in decision-making bodies or levels. (Site 1, Person with Disability)*

*People with disability must know those laws and policies that were established for them so that they play a role in their implementation. (Site 2, OPD and Person with Disability)*

## ■ Togo

Participants drew clear links between education, the dignity afforded by employment, and positive effects on the self-confidence of persons with disabilities:

*We will have to help our children to study. This is the only way to succeed today. (Site 1, Person with Disability)*

*In my opinion, only work [income-generating activity] can enable the disabled person to have more control over his or her life. Through livelihood, they will have money to take care of themselves. (Site 2, Person with Disability)*

The position is encapsulated in the following statement:

*A disabled woman who carries out an income-generating activity and is autonomous will necessarily have the respect of others ... If people with disabilities start reaching out and get a job, it will change the prejudices against them. Only work can give respect to people with disabilities. (Site 2, Person with Disability)*

#### ■ Zimbabwe

For members of the Zimbabwean group, increasing confidence and control over one's life hinged on improved integration and acceptance of persons with disabilities in the community, which must occur alongside initiatives to grow awareness of disability as an equity issue.

*There is need for integration and orientation of those that are able bodied, without disabilities, so that they appreciate those with disabilities. Issue that is there is that, if you have never lived with someone who has disabilities, you will not know of their capabilities, or if you have never got any orientation on what happens with a person who has a disability, you will always look down upon them because of your perception on people with disabilities, for you think that these people are more like second-class citizens. (Site 1, Person with Disability)*

*Number-one enemy is lack of confidence. You know when you go to the society, we need ourselves to be confident, the disabled ourselves. We need to tell the world what we are made of, and that we have the potential, and we can do it. We can be confident people. (Site 2, Person with Disability)*

### KEY POINTS

- **Parents need support in raising children with disabilities who feel entitled to full inclusion.**
- **Education and sustainable livelihoods are key to building confidence.**
- **Persons with disabilities need acceptance from the community and a diminution of negative attitudes if they are to have greater control in their lives.**

**INDICATOR**

1.A2

**Women, men, girls and boys with disabilities and their families report improved quality support available**

## ■ Cameroon

Members of this group emphasised persons with disabilities' need for not only physical access, but also psychological support if high levels of participation are to be achieved.

## ■ Ethiopia

The Ethiopian group believed that creating a more supportive community depends on strong investment in education on disability access issues.

## ■ Honduras

In addition to the need for psychological support, this group indicated that families required specific assistance in order to provide a supportive network for children with disability:

*There should be support in giving psychological help in my community. (Site 1, Person with Disability)*

*They could be supported in training the families on how to treat the person with disabilities since it is in their homes where they isolate them, and that is where the nicknames are born. We should work with the families, support them with financial assistance or venture into entrepreneurship, so that they can generate their own income. (Site 1, Project Staff)*

One member framed this point as the family's need for a combination of 'moral and logistical support':

*Our family members need moral support because, when there is a person with a disability in a house, what they do is hide them, they are embarrassed to know that they have a disability, we need to raise awareness among the family. (Site 2, Person with Disability)*

*Above all, we need to visit them and meet with them to teach them how to treat people, so that the families feel proud and that we are important. (Site 2, Person with Disability)*

#### ■ India

This group echoed the call for an emphasis on assisting parents and families of children and adults with disabilities in providing a supportive environment:

*The parents need special training for the care of their child. The parents must get financial support, not only for the betterment of the child, but also their own growth. (Site 2, OPD)*

#### ■ Pakistan

This group also focused mainly on the need to assist parents in their role of supporting persons with disabilities:

*We should consult with parents to make the lives of their children with disabilities comfortable. (Site 1, OPD)*

#### ■ Togo

For the Togo group, adequate support in the community depends on the availability of financial resources. It appeared that community members require adequate resources themselves in order to create a more supportive environment for persons with disabilities:

*We want to make people with disabilities comfortable in the best possible conditions, but sometimes it is the financial resources that are lacking. We would have liked us to support our various income-generating activities once again, as INADES had done before. The more stable our financial conditions will be, the better care we will offer to our disabled children. (Site 1, Parent of CWD)*

#### ■ Zimbabwe

This group reiterated the call for adequate financial resources, in particular to support parents and families in creating a supportive environment for adults and children with disabilities:

*There is also a need to support parents and others on the cost of disability. So you see that the children with disabilities, due to the impairments they have, you might notice that there is an additional cost that comes with that. For example, a child in Chegutu is forced to attend a school in Kadoma simply because that will be the nearest school with the necessary facilities that they can use. But no one ever thinks of that cost. This cost can express itself in*

*various formats as well, and support with education and information on how to handle and take care of their children. (Site 1, Carer)*

## KEY POINTS

- **The need for psychological, and not just material support for persons with disabilities was highlighted.**
- **Educating the community on disability as an access and equity issue was seen as essential to providing a more supportive environment.**
- **There was great emphasis on assisting families, including psychological, logistical and financial support, as well as training in disability care and equity issues.**

### INDICATOR

1.A3

**Increased participation of people with disabilities in selected community activities**

#### ■ Cameroon

In this focus group there was a general perception that people with disabilities participated minimally in community activities:

*Very often, person with disabilities do not participate in activities that can bring them something. (Site 1, Focal Point CBID)*

This lack was understood as a product of a broader community that did not welcome or encourage participation by people with disabilities:

*The community does not encourage persons with disabilities in these activities. For example, along the roads there are artists who sing music but are called beggars. It is a cultural activity that is stigmatised because, when it is a person without disability, we motivate them without having a problem. They are not beggars, they are artists. (Site 1, CBR Worker)*



In this excerpt, we see how an activity that embodies cultural participation and the potential for a sustainable livelihood is rendered less achievable to persons with disabilities due to denigrating attitudes from the broader community.

#### ■ Ethiopia

In the Ethiopian focus group discussion, participation in community activities was regarded as 'not inclusive at all' (Site 1, OPD) and 'very low' (Site 1, OPD). This dismally low participation was ascribed variously to 'discrimination' (Site 1, OPD), 'negative attitudes' (Site 2, OPD), and 'awareness problems' (Site 2, OPD).

This unwelcoming environment was seen as a cause of some parents hiding their children with disabilities from the community:

*There was a perception that such things [person with disability] shouldn't be seen by others. (Site 2, OPD)*

On a positive note, one participant commented that community attitudes had improved since the start of the local project run by the Cheshire Foundation.

#### ■ Honduras

In this group, the view of participation in community activities by persons with disabilities was viewed as minimal. One group member gave this account:

*It is difficult for me to participate in community events, such as cultural, social, and religious events. It is difficult for me to walk, because there are not adequate conditions to move around. I like to go to church, but now I do not attend because there is no ramp. I avoid going to my son's school meetings because I have to climb stairs, so I avoid participating in this type of activities. (Site 1, Person with Disability)*

There were, however, some positive stories, including an account of a 23-year-old person living with Down syndrome, who was studying at the CBR Mi Esperanza as a student of the project.

*We are a success story of the Instituto Psicopedagógico Juana Leclerc. (Site 2, Community Leader)*

## ■ Pakistan

A prominent issue in this group was that of families not allowing children and adults with disabilities to move freely through the community and participate in shared activities:

*Permission from family is hardly granted. (Site 1, OPD)*

*Mostly parents do not take their children with them. (Site 1, OPD)*

## ■ Rwanda

Participation of people with disabilities in community life was seen as something which 'rarely happens' (Site 1, Parent of CWD) as it is 'difficult' (Site 1, Parent of CWD). Access to communal areas such as playgrounds were mentioned as problematic. Importantly though, this group turned the discussion to intra-individual issues in persons with disabilities as an influence on participation. The parents quoted below give accounts of how their children have experienced shame, which limits their willingness and ability to participate in shared activities:

*Always they feeling uncomfortable to join others and this factor prevent them to socialise with others in all sports and cultural programmes. (Site 1, Parent of CWD)*

*Children feel anguished when they see that they cannot do what other children are doing. (Site 1, Parent of CWD)*

## ■ Togo

The consensus in this group was more positive, describing communities that were more inclusive. However, these were also communities in which amenities for recreation were scarce:

*There are no great leisure activities here. The only moments of leisure are funerals and some cultural activities. But I think that people with disabilities participate in these activities. Especially with the INADES project, people with disabilities are no longer ashamed or afraid of other people's looks. They take part in socio-cultural activities, they go to funerals, to church, etc. Last year, we made an outing to the neighbouring village for the funeral ceremonies of one of our brothers. We had to see the number of disabled people who had taken part. People were amazed to see us*

*dancing in our tricycles and jumping on crutches. (Site 1, Person with Disability)*

Although communities were, for the most part, regarded as welcoming, long distances and lack of money were cited as reasons why persons with disabilities at times missed out on participating:

*We try to invite them to join us, but they can't because of the distance and also because of their economic conditions. Transport to and from meetings and activities is a bit expensive ... and there are still some people who have not yet understood that they must let us live and enjoy our lives to the full. There are times when you pass by and you notice that people are laughing at you. But others have understood and accept us as we are. In any case, there is always work to be done. (Site 1, Person with Disability)*

#### ■ Zimbabwe

Three major barriers to participation in community activities were highlighted by this group. Interestingly, the discussion began with the issue of inaccessible dissemination of information on cultural events to community members with disabilities:

*I think information dissemination pertaining to these activities does not reach the people with disabilities. (Site 1, Person with Disability)*

The second barrier related to problems of access to the physical environments where cultural events took place, and a lack of money for an entry fee, which may be double as result of the need for an assistant. This is explained in the following statement:

*On recreation, I want to think in terms of a person who has a disability who just wants to go to places where they can have fun and relax, like places where there is a live band of a local artist ... Question is are those places accessible enough to a person with a disability, where one can just go and pay like others? And if I have an assistant I'm walking with, will I be accorded an opportunity to pay for either one of us so that it becomes cheaper to attend the show? (Site 1, Carer)*

Parental and family attitudes were also cited as possible barriers to participation in community events

*The barrier that stop them from participating, it tends to come from the families, because some families are hiding their persons in the homes. They do not want to be known that in that particular house there is a disabled person. So, they tend to hide them. (Site 2, Person with Disability)*

## KEY POINTS

- **Levels of participation were viewed as very poor in many locations.**
- **People with disabilities were not always welcomed or encouraged, and were sometimes stigmatized.**
- **Discrimination, negative attitudes and poor awareness are commonplace.**
- **This unwelcoming environment seems to be both a cause and consequence of families hiding children and adults with disabilities from the community.**
- **Painfully, children with disabilities may feel shame and anguish at being exposed to a discriminating community.**
- **Physical barriers, financial constraints and poor dissemination of information often limit participation.**

## OBJECTIVE 1.B

**Communities use their resources and networks and mobilise to ensure participation of people with disabilities**

### INDICATOR

1.B1

**Number of persons with disabilities who actively participate in decision-making processes at community level**

## ■ Cameroon

In Cameroon, the consensus was that people with disabilities are very poorly represented in community leadership roles, but that this is due to their not having been capacitated to do so. Thus, there needs to be 'capacity building for leaders' (Site 1, CBR Worker). Adding to this, one member commented that:

*[Persons with disabilities are] very much underrepresented in leadership positions and I will not blame the communities, because people with disabilities shy away from leadership positions. They under estimate themselves. (Site 2, OPD Leader)*

## ■ Ethiopia

This group emphasised that persons with disabilities require appropriate education and training in order to fill leadership roles:

*For persons with disabilities to have representation in the arena of leadership or power, the first step is to educate and train them well. I mean education and training are very critical in making persons with disabilities be the leader or hold a certain power. So, to be an effective leader or have good representation in the leadership position, first of all persons with disabilities themselves should be educated and trained by well-educated and trained trainers or teachers is very important. (Site 1, OPD)*

Added to this, it was argued that discriminatory attitudes limited people with disabilities in assuming positions of leadership:

*When we see those holding the leadership position, it's very low/few. Why this is the case? For me, the main reason that really challenges persons with disabilities to hold the leadership position is the attitude problem. Those holding various positions in the government structure and other areas too don't let person with disabilities hold the leadership position. The main reason is their attitude. (Site 2, OPD)*

Another participant went further, arguing that problems with the implementation of laws and policies were a concern:

*The key to bring persons with disabilities to the leadership position or have representation in the leadership position, working hard on the community awareness creation/raising is very critical. Another is realising the laws as stated. This means implementing laws on*

*the ground rather than talking about them and showing them on paper. If the laws are implemented as intended, persons with disabilities doesn't have the problem of coming to the leadership position. (Site 1, OPD)*

#### ■ Honduras

The group from Honduras stated that, in their experience, persons with disabilities are not to be found in positions of leadership:

*In our communities there are no people with disabilities in authority or leadership roles. (Site 1, Family member with Person with Disability)*

#### ■ Pakistan

This group argued that persons with disabilities must be provided with appropriate training to support them in successfully assuming leadership roles. One participant commented:

*They should be provided with an environment and train them; leaders will rise from them. (Site 2, OPD)*

#### ■ Rwanda

For this group, the way to promoting the inclusion of persons with disabilities in leadership roles was education regarding their rights and entitlement to do so:

*People with disability therefore should be sensitised to know their rights for voting or get voted. (Site 2, OPD)*

#### ■ Togo

Education and training for persons with disabilities in a range of skills relevant to leadership and in their rights was viewed as essential, as was changing the attitudes of authorities:

*In our development committees at neighbourhood and village level, people with disabilities are involved. But what about the major positions of responsibility? In order to occupy these positions, it is necessary to have an educational level. But generally speaking, we people with disabilities do not have this level of education. So, to enable our disabled children to take up the challenge, we will have to help them all together so that they go far in their studies. To do this, families must completely change their mentality and trust in*

*the future of people with disabilities. This will be achieved through awareness-raising. It is true that progress has been made; but more needs to be done to reach other very remote communities. (Site 1, Person with Disability)*

*It will depend on our authorities. At the nationality establishment service, for example, there is only one disabled person among all the staff. People with disabilities are also people capable of working and being part of positions of responsibility or decision making. I think the big problem is with our authorities. They don't like to recruit people with disabilities, to the point of wanting to give them a position of responsibility. We are going to work together on this aspect to see what will change at our next meeting. (Site 2, Community Leader)*

#### ■ Zimbabwe

The emphasis in the Zimbabwean group was on a need for a stronger legal and policy framework that promotes the inclusion of persons with disabilities in leadership roles:

*When it comes to leadership, to me the starting point is that there is need for a better legal and policy framework that sort of tell us what persons with disabilities should do, or how they should be included. (Site 1, Carer)*

In addition, the problem of negative attitudes about the capabilities of people with disabilities was cited as influential:

*What needs to be changed is the community's perspective towards a person with disabilities. If we appreciate that we are all the same then everything is much better. We are all equal, but the difference is that someone has a disability and someone is without a disability. So we need our community to be instilled that we are all equal. (Site 1, Person with Disability)*

## KEY POINTS

- **In general, representation of persons with disabilities in leadership roles is believed to be very poor.**
- **There is great emphasis on the need for building capacity through general education and specific training.**
- **Countering negative attitudes about the abilities of persons with disabilities is key.**
- **Internalised oppression is seen as a barrier.**
- **There is a need for stronger laws and policies that demand representation and are better implemented.**

### INDICATOR

1.B2

**Community members are respectful of the rights of persons with disabilities**

#### ■ Cameroon

Discrimination was regarded as commonplace, with one participant saying that a routine belief is that 'persons with disabilities are incompetent' (Site 1, CBR Worker).

Some responsibility for changing this was placed on persons with disabilities themselves, who were challenged to get involved in their communities at every opportunity.

Discrimination was seen as not only happening 'out there' in the community, but also in families:

*In a family of over 50 people, I was the only one with a disability and I was abandoned and rejected. To them, I was to be helped by a certain group of white people or foreigners. (Site 2, OPD Leader).*



Instances of discrimination against persons with disabilities and their families by religious groups were also described:

*We must accompany the family. When a family has a child with disability it is the stigma. They say he is a wizard, etc. If there is no support, the parents cannot bear it. We need psychological support. (Site 1, CBID Focal Point)*

#### ■ Ethiopia

In this group, participants were vocal about the presence of discrimination, although some believed that the situation was improving over time. One participant began by stating:

*The prevalence of disability-based discrimination in our area is not the milder one, rather the dangerous one. (Site 1, OPD)*

A range of damaging and denigrating ideas about persons with disabilities that prevail in their communities were named by group members. Discrimination took place in domains including 'political, social, economic, etc., and different ways' (Site 1, OPD).

One group member stated:

*There is a misconception: thinking that person with disabilities can't work, can't manage their life, are not equal with other members of the community ... are the wrong perception and negative attitude that the community holds toward persons with disabilities. (Site 1, OPD)*

It was claimed that adults and children with disabilities were commonly seen as:

*... beggars and those living on the street, and such attitude is prevalent. (Site 1, OPD)*

An alternative and more hopeful view was also expressed:

*In the past there was disability-based discrimination. They hate us, they insult us, there was huge discrimination. In the schools, they don't approach us. As to me right now, there is no such disability-based discrimination. I don't know others' [views]; this is my view. We are living together now. (Site 2, OPD)*

One participant identified the local CBID project as helping alleviate discrimination:

*Now since two or three years after this project has started working here, there are huge improvements. ... Now persons with disabilities will participate in different stages/meetings, they will be invited to various social gatherings, they will be treated as human beings, they will also compete for various work. In the past, there was disability-based discrimination in the various competition too. But for two or three years we are observing huge betterment in this area. (Site 2, CBR)*

#### ■ Honduras

Here, improvements in levels of discrimination were reported, but only in areas touched by local community development projects. For instance:

*In this municipality there is a lot of discrimination because the authorities do not care about this vulnerable sector in the community. (Site 1, Community Leader)*

However, where the CUSO project was implemented, positive changes were identified:

*There is no discrimination, bullying or mockery. There is a group of people with disabilities in our community, and in that sense we have not suffered. From the authorities, we do not have any support. We have not received support until now that CUSO discovered us. (Site I, Family Member with Person with Disability)*

Broadly though, discrimination remained a familiar reality, requiring many forms of mobilisation if it is to be overcome:

*Although we have been working on it, there is discrimination in our community. We have trained teachers, parents, community leaders, but we need to focus more, work more in the community so that there is no longer discrimination. ... We need to campaign, we need as leaders, as people who work for people with disabilities, to emphasise more that people with disabilities should have support, to emphasise more so that there is no longer discrimination. (Site 2, Person with Disability)*

## ■ India

The discussion in this group highlighted that 'ignorance' is a key driver of ongoing discrimination. The following statement describes stigmatizing beliefs about disability:

*There is a lady in my neighbourhood who has cerebral palsy. There is a pregnant lady in neighbourhood whose family asks her not to visit the family of that child, saying that you may also end up having a child with cerebral palsy. (Site 1, Parent with CWD)*

However, the work of community projects was seen as having a positive effect:

*Previously in Gram Sabha and Palli Sabha meeting, common people were hating the persons with disabilities. But now the time has changed. Now the persons with disabilities are integral part of the Gram Sabha and Palli Sabha meeting. They are accepted without any discrimination. (Site 2, CBR Staff)*

## ■ Pakistan

Exceptionally in this part of the discussion, the Pakistan group did not highlight any problems regarding discrimination:

*Our community is well aware now and respect persons with disability. We give them opportunity to develop. (Site 1, OPD)*

## ■ Rwanda

In Rwanda, discrimination was named as commonplace, but improvements in the situation were noted:

*Discrimination based on disability is apparent ... it is noticeable everywhere. (Site 1, Parent of CWD)*

*In reality, discrimination to people with disability is visible but it is not like before in previous years, because there are administrative levels that advocate for people with disability. But it still exists. (Site 2, OPD and Person with Disability)*

## ■ Togo

In an emotive discussion, participants from Togo gave painful accounts of discrimination in their communities:

*Discrimination still exists. (Site 2, Person with Disability)*

*In the streets, we often get looks of hatred and disgust. People don't want our children to come near them or touch their belongings. It's really hard. (Site 2, Parent of CWD)*

*The children and some passers-by throw stones at him. (Site 2, Parent of CWD)*

Painfully, families of children and adults with disabilities were identified as a source of discrimination:

*Our parents are the first to discriminate us. They hate us more because for them we can't do anything. They are the ones who annoy us more. Most of them are like that. (Site 2, Person with Disability)*

While small improvements associated with community projects were identified, the overall picture was negative:

*Nowadays in Adeta, discrimination against people with disabilities has slightly decreased thanks to INADES' initiatives. But there are still families who, due of attachment to traditional values or ignorance, still see disability as a fatality or a curse and sideline people with disabilities. You won't see them discriminate in public in front of others, but they do so in secret through acts of contempt. And frankly, sometimes it is humiliating. (Site 1, Parent of CWD)*

## ■ Zimbabwe

The discussion on discrimination began with the family, before moving outwards to the school, and then to the world of employment. First, the family:

*Discrimination is there because most of us are hidden in these houses; they are hidden to such an extent that no one knows that the house has someone with a disability. It starts with the family of origin. Instead of letting the person go outside and interact with others, they instead hide the person. So discrimination starts from the family. (Site 2, Person with Disability)*

Discrimination in schools was described as follows:

*There is also discrimination even at schools to the children. Instead of the child eating with others, they are segregated and eat alone. We are grateful nowadays that there is inclusive in schools, but however discrimination is too much. People look down upon others. Other people instead of looking at you as just another person they actually look at you like an outcast and get a cloth. Discrimination is too much. (Site 2, Person with Disability)*

Creating a disturbing picture of how discrimination follows young people with disabilities through their developmental years and into adulthood, circumstances at places of work were described as follows:

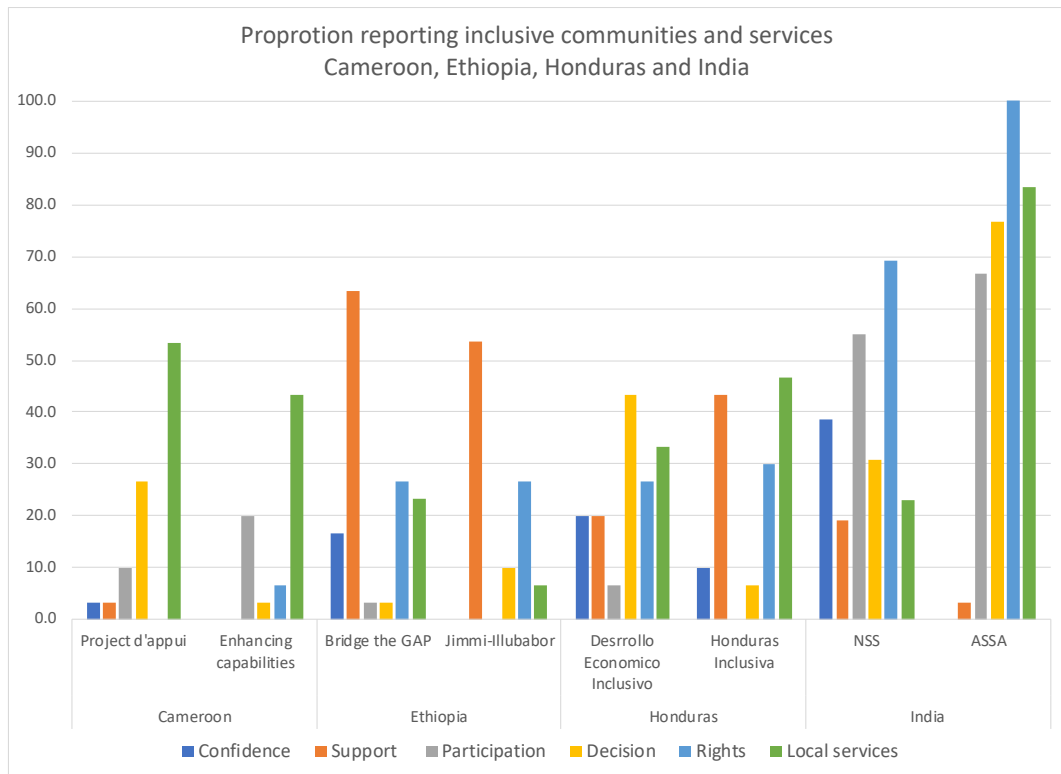
*People have the notion that even in supermarkets such as OK, Pick n Pay, you will not meet an employee with a disability. Because people have the attitude that if you employ someone with a visual or hearing impairment then that shop becomes blind. (Site 1, Person with Disability)*

One member summarised the high levels of discrimination as follows:

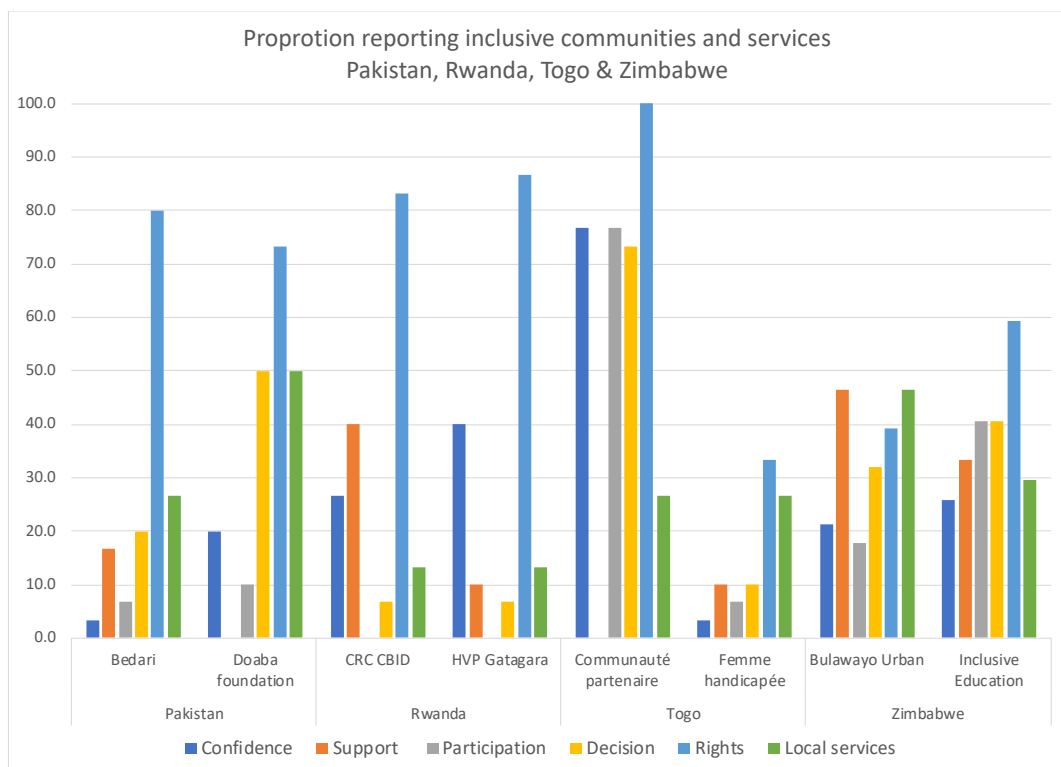
*The community at large is ignorant about the issue of disabilities. There is need that the government intervene so that the community is sensitised ... The community at large has no knowledge about disabilities for they think that disability is something that can be transmitted. (Site 1, Carer)*

## KEY POINTS

- **All groups described disturbingly high levels of discrimination.**
- **Negative stereotypes about the abilities of people with disabilities were commonplace, along with responses of hatred and disgust.**
- **Some progress was noted around the work of CBID projects.**
- **There was a strong emphasis on the painful reality of discrimination within families.**
- **Families can also be victims of discrimination, along with their members who have disabilities.**
- **Institutional discrimination is present in schools and places of work.**



**Figure 4:** Proportion of participants endorsing indicators suggesting inclusive communities and inclusive systems (Cameroon, Ethiopia, Honduras, India).



**Figure 5:** Proportion of participants endorsing indicators suggesting inclusive communities and inclusive systems (Pakistan, Rwanda, Togo, Zimbabwe).

**Table 6:** Participants endorsing indicators suggesting inclusive communities and systems.

	<b>CAMEROON</b>					
	All		Project d'Appui		Enhancing Capabilities	
	N	%	N	%	N	%
Self-confidence	1	1.7	1	3.3	0	0
Quality support	1	1.7	1	3.3	0	0
Participation	9	15.0	3	10.0	6	20.0
Decision-making process	9	15.0	8	26.7	1	3.3
Respectful of rights	2	3.3	0	0	2	6.7
Inclusive local services	29	48.3	16	53.3	13	43.3
<b>ETHIOPIA</b>						
	All		Bridge the GAP		Jimma-Illubabor	
Self-confidence	5	8.3	5	16.7	0	0
Quality support	35	58.3	19	63.3	16	53.3
Participation	1	1.7	1	3.3	0	0
Decision-making process	4	6.7	1	3.3	3	10.0
Respectful of rights	16	26.7	8	26.7	8	26.7
Inclusive local services	9	15.0	7	23.3	2	6.7
<b>HONDURAS</b>						
	All		Desarrollo Económico		Honduras Inclusiva	
Self-confidence	9	15.0	6	20.0	3	10.0
Quality support	19	31.7	6	20.0	13	43.3
Participation	2	3.3	2	6.7	0	0
Decision-making process	15	25.0	13	43.3	2	6.7
Respectful of rights	17	28.3	8	26.7	9	30.0
Inclusive local services	24	40.0	10	33.3	14	46.7
<b>INDIA</b>						
	All		NSS		ASSA	
Self-confidence	10	17.9	10	38.5	0	0.0
Quality support	6	10.7	5	19.2	1	3.3
Participation	34	60.7	14	53.8	20	66.7
Decision-making process	31	55.4	8	30.8	23	76.7
Respectful of rights	48	85.7	18	69.2	30	100.0
Inclusive local services	31	55.4	6	23.1	25	83.3

PAKISTAN						
	All		Bedari		Doaba Foundation	
Self-confidence	7	11.7	1	3.3	6	20.0
Quality support	5	8.3	5	16.7	0	0
Participation	5	8.3	2	6.7	3	10.0
Decision-making process	21	35.0	6	20.0	15	50.0
Respectful of rights	46	76.7	24	80.0	22	73.3
Inclusive local services	23	38.3	8	26.7	15	50.0

RWANDA						
	All		GRC CBID		HVP Gatagara	
Self-confidence	20	33.3	8	26.7	12	40.0
Quality support	15	25.0	12	40.0	3	10.0
Participation	0	0	0	0	0	0
Decision-making process	4	6.7	2	6.7	2	6.7
Respectful of rights	51	85.0	25	83.3	26	86.7
Inclusive local services	8	13.3	4	13.3	4	13.3

TOGO						
	All		Communauté Partenaire		Femme Handicapée en Action	
Self-confidence	24	40.0	23	76.7	1	3.3
Quality support	3	5.0	0	0	3	10.0
Participation	25	41.7	23	76.7	2	6.7
Decision-making process	25	41.7	22	73.3	3	10.0
Respectful of rights	40	66.7	30	100.0	10	33.3
Inclusive local services	16	26.7	8	26.7	8	26.7

ZIMBABWE						
	All		Bulawayo Urban		Inclusive Education	
Self-confidence	13	23.6	6	21.4	7	25.9
Quality support	22	40	13	46.4	9	33.3
Participation	16	29.1	5	17.9	11	40.7
Decision-making process	20	36.4	9	32.1	11	40.7
Respectful of rights	27	49.1	11	39.3	16	59.3
Inclusive local services	21	38.2	13	46.4	8	29.6

## Overview of findings

- On average, across countries, half of the study participants reported not having experienced discrimination on the basis of disability, suggesting the community is respectful of rights of persons with disability. This differs hugely across countries, however, as nearly all participants reported experiencing discrimination in Cameroon (n=58, 93.3%), whereas that was the case for less



than 30% of participants in India, Pakistan and Rwanda. Even within countries, the discrepancies were significant between projects (e.g. Togo and India).

- Self-confidence (n=89, 18.9%) and participation in community activities (n=92, 19.5%) were the least reported across countries. The discrepancies across countries and projects indicate the need to address inclusive development in a targeted way, depending on the location and context.
- None of the participants reported voting in the last election, which indicates a gap in persons with disabilities' participation in decision-making processes at community level.



## Priority Area 2 Inclusive systems

For **Priority Area 2: Inclusive systems**, assessments were made of how closely communities approximated the ideal:

*Services and support systems are inclusive and functioning effectively in the community.*

Below is a summary of Priority Area 2 objectives and indicators, followed by an outline of the research findings by indicator.

<b>Priority Area 2: Inclusive systems</b>	
Services and support systems are inclusive and functioning effectively in the community	
<b>Objective</b>	<b>Indicators</b>
<b>A.</b> Mainstream and individual disability-specific services are of good quality, accessible, available, affordable, and accepted by all at community level	<ol style="list-style-type: none"> <li><b>1.</b> Increased number of persons with disabilities accessing local services</li> <li><b>2.</b> Increased number of assistive devices provided</li> <li><b>3.</b> A multisectoral network of service providers is available to the community</li> </ol>

**OBJECTIVE 2.A**

**Mainstream and individual disability-specific services are of good quality, accessible, available, affordable, and accepted by all at community level**

To assess how services and support systems are inclusive and functioning effectively in communities at baseline and over, participants were asked to rate how satisfied they were with the level of respect they were treated with during their last visit to a health care provider, as well as whether they had accessed health care or rehabilitation services they felt they needed. These are reported in Table 7 by country and project. The participants' self-rated health and use of aids is also reported in Table 7.

**Table 7:** Level of inclusivity of services and support systems by country and project.

	<b>CAMEROON</b>					
	All		Project d'Appui		Enhancing Capabilities	
	Mean	SD	Mean	SD	Mean	SD
Self-rated health (0–4)	3.3	0.76	3.4	0.67	3.2	0.83
Level of respect from HCP (0–4)	2.8	0.94	2.8	1.18	2.8	0.63
	N	%	N	%	N	%
Unable to get care needed <sup>a</sup>	23	52.3	13	56.5	10	47.6
Unable to get rehab needed <sup>b</sup>	24	60.0	13	72.2	11	50.0
Use of functioning aids <sup>c</sup>	17	28.3	8	26.7	9	30.0
	<b>ETHIOPIA</b>					
	All		Bridge the GAP		Jimma-Illubabor	
	Mean	SD	Mean	SD	Mean	SD
Self-rated health (0–4)	2.4	1.21	2.7	1.09	2.1	1.28
Level of respect from HCP (0–4)	1.9	0.81	2.1	0.84	3.7	0.74
	N	%	N	%	N	%
Unable to get care needed <sup>a</sup>	16	45.7	12	70.6	4	22.2
Unable to get rehab needed <sup>b</sup>	2	14.3	2	25.0	0	0
Use of functioning aids <sup>c</sup>	33	55.0	18	60.0	15	50.0
	<b>HONDURAS</b>					
	All		Desarrollo Económico		Honduras Inclusiva	
	Mean	SD	Mean	SD	Mean	SD
Self-rated health (0–4)	2.5	0.65	2.5	0.73	2.6	0.56
Level of respect from HCP (0–4)	3.2	0.88	3.1	0.66	3.2	1.06
	N	%	N	%	N	%
Unable to get care needed <sup>a</sup>	13	37.1	7	38.9	6	35.3
Unable to get rehab needed <sup>b</sup>	8	80.0	2	66.7	6	85.7
Use of functioning aids <sup>c</sup>	13	21.7	6	20.0	7	23.3
	<b>INDIA</b>					
	All		NSS		ASSA	
	Mean	SD	Mean	SD	Mean	SD
Self-rated health (0–4)	2.8	0.5	2.7	0.62	3.0	0.32
Level of respect from HCP (0–4)	2.8	1.37	2.1	1.61	3.4	0.72
	N	%	N	%	N	%
Unable to get care needed <sup>a</sup>	5	45.5	4	40.0	1	100
Unable to get rehab needed <sup>b</sup>	7	70.0	6	66.7	1	100
Use of functioning aids <sup>c</sup>	0	0	0	0	0	0

	PAKISTAN					
	All		Bedari		Doaba foundation	
	Mean	SD	Mean	SD	Mean	SD
Self-rated health (0–4)	3.0	0.70	2.7	0.66	3.4	0.56
Level of respect from HCP (0–4)	2.5	1.00	2.5	0.94	2.5	1.07
	N	%	N	%	N	%
Unable to get care needed <sup>a</sup>	39	79.6	19	82.6	20	76.9
Unable to get rehab needed <sup>b</sup>	14	63.6	7	58.3	7	70.0
Use of functioning aids <sup>c</sup>	26	43.3	7	23.3	19	63.3

	RWANDA					
	All		GRC CBID		HVP Gatagara	
	Mean	SD	Mean	SD	Mean	SD
Self-rated health (0–4)	1.9	0.70	1.9	0.73	1.9	0.68
Level of respect from HCP (0–4)	2.3	0.65	2.3	0.65	2.3	0.65
	N	%	N	%	N	%
Unable to get care needed <sup>a</sup>	34	72.3	15	62.5	19	82.6
Unable to get rehab needed <sup>b</sup>	34	72.3	15	62.5	19	82.6
Use of functioning aids <sup>c</sup>	12	20.0	4	13.3	8	26.7

	TOGO					
	All		Communauté Partenaire		Femme Handicapée en Action	
	Mean	SD	Mean	SD	Mean	SD
Self-rated health (0–4)	2.5	0.95	3	0.89	2.1	0.8
Level of respect from HCP (0–4)	3.1	1.01	3.4	0.72	2.8	1.19
	N	%	N	%	N	%
Unable to get care needed <sup>a</sup>	27	57.4	19	65.5	8	44.4
Unable to get rehab needed <sup>b</sup>	2	8.3	2	10.5	0	0
Use of functioning aids <sup>c</sup>	12	20	8	26.7	4	13.3

	ZIMBABWE					
	All		Bulawayo Urban		Inclusive Education	
	Mean	SD	Mean	SD	Mean	SD
Self-rated health (0–4)	3.1	1.28	2.8	1.52	3.3	0.95
Level of respect from HCP (0–4)	2.7	1.38	2.9	1.39	2.5	1.37
	N	%	N	%	N	%
Unable to get care needed <sup>a</sup>	19	46.3	8	40.0	11	52.4
Unable to get rehab needed <sup>b</sup>	7	33.3	2	50.0	5	29.4
Use of functioning aids <sup>c</sup>	7	12.7	4	14.3	3	11.1

HPC = Health Care Provider; SD = Standard Deviation; <sup>a</sup> Among those who needed care; <sup>b</sup> Among those who needed rehabilitation services; <sup>c</sup> Greater score means better health

**INDICATOR**

2.A3

**A multisectoral network of service providers is available to the community**

As for inclusive communities, responses on the inclusive health systems subscale were measured at individual level and dichotomised to identify participants satisfied with health services. This was defined as someone:

- indicating being in good or very good health, *and*
- being mostly or completely satisfied with the level of respect they were treated with at their last visit to a health care provider, *and*
- being able to get health care or not needing health care, *and*
- being able to get rehabilitation services or not needing such services.

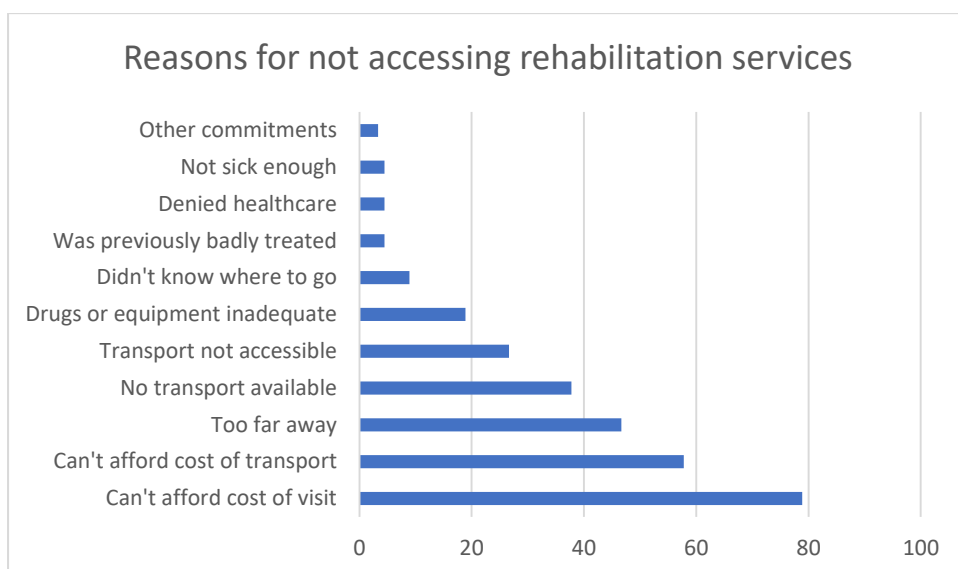
The proportion reporting being satisfied with health services, by country and project, is reported in Figures 3 and 4, and summarised in Table 5.

### **Overview of findings**

Over one-third (n=161, 34.2%) indicated good health, receiving the care they needed, and being treated with respect in health care settings, suggesting that local services may be inclusive and functioning, although other indicators at community level are required for this inference to be made.

### **Access to rehabilitation**

Of the 471 participants across all countries, only 90 participants (19.1%) reported not accessing rehabilitation services even though they felt they needed them. The reasons for not accessing care mostly related to not being able to afford the cost of the visit or transport to the facility (Figure 6).



**Figure 6:** Reasons reported for not accessing rehabilitation services (n=90)

Access issues for persons with disabilities is a fundamental and needs to be addressed in order to assess their life situation. The three main issues – access to health, education, and livelihoods – are discussed separately, although they are interconnected and part of a more complex system.

### Access to health care

#### ■ Cameroon

Participants from Cameroon highlighted a range of barriers to accessing health care. These included:

- Physical barriers

*There are no ramps.* (Site 1, Parent of CWD)

*We have to carry the sick.* (Site 1, Parent of CWD)

- Attitude barriers

*There is a problem with staff attitudes towards person with disability.* (Site 1, CBR Worker)

- Financial barriers

*Cost of service.* (Site 1, CBR Worker)

## ■ Ethiopia

A participant in Ethiopia remarked:

*There are huge gaps in accessibility. (Site 1, CBIR)*

Despite this, another participant pointed to positive changes emanating from the work of the local development project:

*Now there is improvement ... after this project started working here, there are improvements. We were given many wheelchairs. We are observing many betterments. And this should be strengthened. (Site 2, OPD)*

## ■ India

Participants in this group noted:

*There is a lot of trouble in accessing medical care. (Site 1, Parent of CWD and OPD)*

To this, a parent of a child with disability added:

*It is a big challenge for us to get treatment for our children. (Site 1, Community Member)*

Some respondents spoke about having to go to private medical facilities, which cost more money. One participant went as far as saying:

*The facilities never reach us, especially the poor. We do not even get to know about those. (Site 1, Community Member)*

## ■ Pakistan

In the Pakistan group, similar circumstances were described:

*Mostly hospitals are not accessible, (Site 1, Person with Disability)*

However, added to this picture was a positive account of community support in accessing health care:

*I personally observed and seen some rickshaw drivers and some vehicle owners have displayed at their vehicles that they will not take fare from persons with disabilities for travelling to hospital. This, this is my observation. I felt it very good. I saw a few people are doing this voluntarily. (Site 2, OPD)*



## ■ Rwanda

Long distances to health installations and the need for financial resources, including health insurance, were named by this group.

*Problems found in health service sector are that these services are far away from where people with disabilities live and not all services are covered by community based health insurance. (Site 1, Local Leader)*

In Rwanda another important issue was parents' experience of stigma when taking their children with disabilities to health services:

*Parents have that thing (but not all) of not taking their children to health facilities because of stigma and discrimination issues. (Site 1, Disability Officer)*

Overall, poverty was regarded as a key barrier to accessing health care.

## ■ Togo

While access to health services remains an issue, it was felt that encouraging progress has been made through the work of NGO development projects:

*In hospitals today, there is still a lot to be done to alleviate the pain of people with disabilities. (Site 2, Project Team Member)*

*NGOs have played a very important role in this respect, in particular the construction of ramps in health facilities, awareness-raising and the donation of tricycles to people with disabilities to facilitate their access to health facilities in Adeta. (Site 1, Person with Disability)*

### KEY POINTS

- **Physical, attitudinal and financial barriers to accessing health care are commonplace.**
- **In some countries, significant improvements are attributed to the work of community development projects.**
- **Some parents experience stigma when taking their children with disabilities to health care locations, sometimes resulting in avoidance.**

## Access to education

### ■ Cameroon

In Cameroon, one participant bluntly stated:

*Schools are not suitable for persons with disabilities. (Site 1, CBID Focal Point)*

Much of the problem is attributed to inadequate teacher training:

*Even the teacher doesn't know what to do. It is also a problem of teacher training which does not take disability into account. (Site 1, CBID Focal Point)*

This problem with the services offered by schools was compounded, in the view of this group, by parents who were ambivalent about the education of their children with disabilities.

### ■ Ethiopia

The theme of parents' role in limiting access to education was picked up in the Ethiopian discussion:

*There are children with disabilities and persons with disabilities kept being hidden in the home/house so far, there are community members or parents of persons with disabilities/CWD who are saying 'I feel ashamed to take you to the school today'. (Site 1, OPD)*

However, it was also noted that:

*Schools are not persons with disabilities friendly. (Site 2, OPD)*

### ■ India

In this group, the consensus was that access to education was extremely poor:

*No, they do not get it. They do not have money; they are also poorly educated. Even if they are educated, they do not have money, nobody gives them training. So, they are mostly dependent upon their parents. (Site 1, Parent of CWD)*

## ■ Pakistan

The role of parents in exclusion was highlighted:

*Even our parents do not give right of equality to disable children.  
(Site 1, OPD)*

A teacher who was part of the group related parent-based exclusion of children with disabilities to the same phenomenon in relation to girls:

*I am a teacher. We go door to door for enrolment of girls. But parents do not send them to schools. They say that girls will remain at home. They say these are not their part. They do not let them go to schools to get education. (Site 1, Teacher)*

One participant in this group powerfully illustrated the systemic ways in which exclusion from education takes place:

*First of all his parents do not accept that he/she continue study. If he got permission, he does not catch the transport on time. If he catch it, transport will not be accessible. If transport is accessible, and he reached schools after push-ups, admission will not be given to them. If admission is granted, ramps are not available in institutions; if ramps are available, washrooms will not be accessible. Means he is facing issues at each step. (Site 2, Programme Manager)*

## ■ Rwanda

In Rwanda, five issues were raised around access to education: a lack of schools, the mind-set of children with disabilities, the perceptions of parents of children with disabilities, money and transportation, and the attitudes of teachers. On the last issue, one participant commented:

*Some teachers who hurt our children with disability. (Site 1, Parent of CWD)*

Such problems were associated with a lack of teacher training:

*There is also another problem of training of teachers. Teachers were not trained on various teaching methods to children with disability. Therefore, these make children with disability embarrassed. (Site 1, Disability Officer)*

The issue of cost and distance to schools was highlighted:

*To me, things related to education of children with disability, there are obstacles. Schools are still very few and it is not easy for many parents to send their children to this school because it is very far. Sometimes it requires parents with children with disability to rent accommodation near the school, but not all have the financial means. Therefore, schools should be many so that children with disability can access them nearby where they live. (Site 2, Disability Officer)*

#### ■ Togo

Discussion of barriers to education began with attitudes:

*The worst case is that they are not welcome in schools because the teachers find it very difficult to supervise them, and their classmates are not very courteous towards them. These facts do not allow them to continue their studies. (Site 1, Project Team Member)*

This led on to the vexed 'question of qualified teachers' (Site 1, Parent of CWD), which was regarded as 'still a problem in our schools' (Site 1, Parent of CWD).

One participant linked the issues of access to health and access to education:

*Disabled children need to be in good health to be able to go to school. (Site 2, Parent of CWD)*

One parent provided a clear example of how exclusion of children with disabilities may unfold:

*My child suffers from an intellectual disability and is very often restless. I put him in a public school, but when his classmates provoke him and he gets angry he becomes violent. As a result, the teachers no longer accepted his presence; I had to re-enrol him in a public school where it didn't work. Now he is at home. It is in view of this situation that I suggest that we create a special school in our community to provide better care for our disabled children. (Site 2, Parent of CWD)*

## ■ Zimbabwe

Here, the issue of teacher education was raised, in statements such as:

*In these schools there is need to train more teachers who would be able to help the disabled people. (Site 2, Person with Disability)*

### KEY POINTS

- **Inadequate training of teachers is a pervasive problem, sometimes leading to discrimination.**
- **Inaccessible built environments and the prohibitive cost of transportation are key factors.**
- **Shame or ambivalence of parents leads to exclusion.**

## Access to livelihood

### ■ Cameroon

As one participant in Cameroon bluntly put it:

*Access is very difficult. There is little training so it is difficult to get to work. (Site 1, Parent of CWD)*

There often seems to be a charity approach to livelihoods:

*They look at us as the end and they give us rice. They don't look at us as people who can be trained so that we can also give others rice ... Therefore, livelihood opportunities are very scarce for persons with disabilities. In some cases it is done ignorantly by some individuals, but in some it is done intentionally. (Site 2, OPD Leader)*

### ■ Ethiopia

According to one participant in Ethiopia:

*[Organisations think that] persons with disabilities/CWD are not capable of working and managing their life; persons with disabilities/CWD don't have opportunities and rights as that of other community members; persons with disabilities/CWD are useless for the nation in general and themselves in particular. (Site 1, OPD)*

#### ■ Honduras

Participants in Honduras linked the lack of access to jobs to employers' lack trust that persons with disabilities have the capacity to do the job. One participant stated:

*People with disabilities are still discriminated when they want to get a job, they do not trust that they can have the capacity.*  
(Site 2, Person with Disability)

#### ■ India

Finding employment is perceived to be difficult for persons with disabilities, and often results in suffering:

*Persons with disabilities find it even more difficult to find any employment. They are always told that they cannot do anything ... Almost all persons with disabilities are suffering.* (Site 2, Community Leader)

#### ■ Pakistan

In Pakistan, participants were more positive about livelihoods:

*They were provided with skill trainings of developing small enterprises and vocational skills under CBID program.* (Site 1, Person with Disability)

#### ■ Rwanda

Rwanda's discussions centred on the link between lack of access to education and livelihoods:

*What I can say, many people with disability never obtained opportunity to attend school because of the saying that 'people with disability are incapable'. This inhibited their economic development.* (Site 1, Disability Officer)

*It is not easy for people with disability to get jobs or create their own jobs because they never received education like others.*  
(Site 2, OPD and Person with Disability)

#### ■ Togo

The issue of training in livelihoods came across as quite a significant factor:

*We were taught during the trainings with APROFEHTO agents how to undertake an income-generating activity, how to manage funds, what we can spend and what we need to set aside for our health and other needs. We have received a lot of trainings that are very useful to us. (Site 2, Person with Disability)*

#### ■ Zimbabwe

The Zimbabwean participants emphasised the relationship between education and livelihoods:

*Some livelihoods require education. If you are not educated you will miss out on opportunities instead, you live the life of medieval age, which consists of people with disabilities living through begging. (Site 1, Carer)*

### KEY POINTS

- **Access to livelihood is strongly related to access to education issues.**
- **Persons with disabilities seem to be prone to discrimination, especially from employers', when it comes to access to livelihood issues.**

### Accessibility of transport

#### ■ Cameroon

Participants stated that transport in Cameroon was available but not always accessible:

*Means of transport are available but not accessible. (Site 1, OPD Representative)*

## ■ Honduras

Transport in Honduras is characterised by an unwillingness to transport persons with disabilities:

*What we lack is transportation. Here we use motorcycle cabs and some people do not like to take people with disabilities, because they have to help them and they lose time, according to them. They do not like to transport people with disabilities. (Site 2, Person with Disability)*

## ■ Pakistan

Distances and time issues were highlighted:

*Transport is very far from our villages. It takes one hour of travelling. (Site 1, OPD)*

## ■ Rwanda

Challenges related to transport for persons with disabilities were continuously mentioned by participants:

*Transport for people with disability is still a challenge. (Site 2, CBID)*

## ■ Togo

There were mixed responses from participants about transport:

*Nobody prevents us from having access to public transport. On the other hand, some drivers help us when we have difficulty getting on board. But there are also others who sometimes jostle us. (Site 1, Parent of CWD)*

## ■ Zimbabwe

Issues of harassment and, in some instances, abuse were mentioned when it came to transport issues:

*The availability of transport – transport system is not accessible. When you want to go to town, you are a woman who has a wheelchair or you are a woman on crutches, so without assistance you might end up being harassed. You are prone to sexual abuse and harassment. (Site 2, Person with Disability)*



## KEY POINT

- **Access to transport is problematic in all countries, often caused by discrimination and negative attitudes.**

### Accessibility of housing

#### ■ Pakistan

According to the focus groups in Pakistan, access to housing is connected with awareness issues:

*People have their own houses, but they are not accessible because we have no awareness about making their homes accessible. People have no awareness. (Site 2, OPD)*

#### ■ Togo

Lack of suitable infrastructure in housing and the subsequent negative conditions were highlighted:

*For housing, this is always a problem. Given our physical conditions, we need suitable infrastructures. But it's a pity that this is not the case. Most of our houses don't have latrines. In order to meet our needs, we have to go digging in the bush. Imagine a person with a disability travelling on his or her own to go into the bush and dig to meet his or her needs. Can you imagine? Or even sometimes the showers are really not adapted to their conditions. A disabled person who is going to crawl with his or her hand to go to the toilet or take a bath. It's disgusting, isn't it? Especially in the rainy season, it's very annoying, and for us who are allergic, it complicates our lives. (Site 1, Person with Disability)*

## KEY POINT

- **Access to housing is mentioned as problematic in some countries. However, more research is needed on this topic.**

## SUMMARY

Like any data collection across geographical and cultural borders, involving diverse participants in complex community settings, this baseline study comes with a series of caveats.

First of all, this is not a comprehensive study about the situation of people with disabilities in inclusive community development; neither does it claim to be. It is not meant to generalise the disability experience in the locations in which this baseline was conducted; neither does it claim to create a generic model for the implementation of inclusive community development. It provides partial and contextualised findings, narratives, and critical reflections on specific issues around CBID that will be followed up in further data collection phases (2022 and 2024) and might, at this moment, provide some food for thought around what information needs to be considered for future progress, monitoring or assessments.

Secondly, while this study draws on research from eight countries, it does not claim to represent and/or speak for disabled persons throughout these countries. The communities that were part of this research are as complex, diverse and hybrid as they are resistant to homogenisations and simplifications. Indeed, much of this baseline study is devoted to exploring and highlighting the various nuances around the pre-identified indicators of the CBM CBID Initiative Plan, and enriching the understanding of the communities in which CBM's project partners operate. This includes identifying problem areas in order to facilitate improvement in the implementation of CBID work in these communities.

The data generated reveals some common issues for persons with disabilities in the participating CBID programmes, particularly around discrimination, access to services, lack of participation in community activities, and decision-making processes at community level, as well as the poor representation of persons with disabilities in leadership roles. This data, however, differs in some of these areas (e.g. discrimination), across countries, and sometimes between projects in one country. CBID on the ground is being practiced in different ways in different geographical, political, economic, and cultural environments. The diverse outcomes in some of the areas researched indicate the need to address, in practice, these

programmatic issues and approaches in a targeted way, depending on the local context.

The findings of this baseline study also provide first insights on the inherent interrelatedness of areas such as education, health, and livelihood. As described in some of the focus group discussions, lack of education due to lack of access to transport or financial barriers can lead to decreased access to livelihood opportunities. This shows that complex issues cannot be adequately comprehended in isolation from the wider system of which they are part. It is therefore recommended that analysis in the subsequent phases of this longitudinal study (2022 and 2024) includes how and to what effect multi-scale and interconnected areas in inclusive community development interact and connect. This knowledge has the potential to effectively help to build skills in CBID programmes to guide complex programming processes appropriately and in a more targeted way.

There are indications in the baseline data that suggest community stakeholders in some places attribute improvements in some areas, such as stigma prevention and community awareness, to the work of the local CBID programme. Training and education measures were highlighted as key. These assumptions need in-depth investigation during the rollout of the longitudinal study.

## APPENDIX A: SURVEY QUESTIONS (English)

A – Introduction and demographic information				
A1	[Country]	Cameroon		country
		Ethiopia		
		Honduras		
		India		
		Pakistan		
		Rwanda		
		Togo		
		Zimbabwe		
A2	What is your home language?	French		language
		Amharic		
		Oromiffa		
		Spanish		
		Hindi		
		Odia		
		Urdu		
		Kinyarwanda		
		Shona		
A3	How old are you?			age
A4	[Gender]	Male	1	gender
		Female	2	
A5	What is your highest level of education?	No education/illiterate	1	edu
		Some education	2	
		Completed primary education	3	
		Completed secondary education	4	
		Tertiary education	5	
A6	What is your current employment status?	Self-employment (including subsistence farmer)	1	emp
		Full- or part-time employment by someone else (wage or salaried)	2	
		Voluntary employment (unpaid)	3	
		Not employed (including housewife, student, pensioner)	4	
A7	Do you live alone?	No	0	livealone
		Yes [→ go to A8]	1	

A8	Who do you live with?	Family of origin	1	livewith
		Spouse and/or children	2	
		Other	3	
<b>What type of disability do you have?</b>				
A9	Mobility/physical	No	0	dis_phys
		Yes	1	
A10	Spinal cord	No	0	dis_spinal
		Yes	1	
A11	Head injury	No	0	dis_head
		Yes	1	
A12	Vision	No	0	dis_vision
		Yes	1	
A13	Hearing	No	0	dis_hearing
		Yes	1	
A14	Intellectual/cognitive	No	0	dis_cog
		Yes	1	
A15	Neurological	No	0	dis_neuro
		Yes	1	
A16	Psychosocial	No	0	dis_psych
		Yes	1	
A17	[Has the participant been informed about the aim of the research?]	No	0	aims
		Yes	1	
A18	[Has participant been informed that the information they provide would be confidential?]	No	0	confidential
		Yes	1	
A19	[Has the participant provided written consent to participate in the research?]	No [-> end of questionnaire]	0	consent
		Yes	1	
A20	Date of interview	DD : MMM : YYYY		
A21	[Participant ID]			pid
<b>B – Communities are inclusive of all people with disability</b>				
<b>Self confidence</b>				
B1	Do you get to make the big decisions in your life? <i>[For example, deciding who to live with, where to live, or how to spend your money?]</i>	Not at all	1	decisions_life
		A little	2	
		Moderately	3	
		Mostly	4	
		Completely	5	
B2	Are you satisfied with your ability to persuade people of your views and interests?	Not at all	1	persuade
		A little	2	
		Moderately	3	
		Mostly	4	
		Completely	5	

B3	Do you get to make decisions about the personal assistance that you need? <i>[Who assists you, what type of assistance, when to get assistance?]</i>	Not at all	1	decisions_assist
		A little	2	
		Moderately	3	
		Mostly	4	
		Completely	5	
B4	To what extent do you know your legal rights?	Not at all	1	rights
		A little	2	
		Moderately	3	
		Mostly	4	
		Completely	5	
B5	Do you get to decide how to use your money?	Not at all	1	money
		A little	2	
		Moderately	3	
		Mostly	4	
		Completely	5	
<b>Quality support</b>				
Instructions: I am going to ask you some general questions about your environment and your social relationships. I want you to answer the following questions on a scale from 1 to 5, where 1 means very easy and 5 means very hard.				
B6	Does your workplace or educational institution make it easy or hard for you to work or learn?	??[range 1-5]		easy_work
		Not applicable	66	
		Don't know	88	
B7	Do health facilities you need regularly make it easy or hard for you to use them?	??[range 1-5]		easy_facilities
		Not applicable	66	
		Don't know	88	
B8	Do places where you socialise and engage in community activities make it easy or hard for you to do this?	??[range 1-5]		easy_socialise
		Not applicable	66	
		Don't know	88	
B9	Do the shops, banks and post office in your neighbourhood make it easy or hard for you to use them?	??[range 1-5]		easy_shops
		Not applicable	66	
		Don't know	88	
B10	Do your regular places of worship make it easy or hard for you to worship?	??[range 1-5]		easy_worship
		Not applicable	66	
		Don't know	88	
B11	Does the transportation you need or want to use make it easy or hard for you to live there?	??[range 1-5]		easy_transport
		Not applicable	66	
		Don't know	88	

<b>Participation</b>				
B12	Do you get to participate in artistic, cultural or religious activities?	Not at all	1	culture
		A little	2	
		Moderately	3	
		Mostly	4	
		Completely	5	
B13	Do you get to participate in community recreational, leisure and sports activities?	Not at all	1	leisure
		A little	2	
		Moderately	3	
		Mostly	4	
		Completely	5	
<b>Decision-making processes</b>				
B14	Do you get to influence the way your community is run?	Not at all	1	influence_com
		A little	2	
		Moderately	3	
		Mostly	4	
		Completely	5	
B15	Do you feel that other people respect you? [ <i>For example, do you feel that others value you as a person and listen to what you have to say?</i> ]	Not at all	1	respect
		A little	2	
		Moderately	3	
		Mostly	4	
		Completely	5	
B16	Did you vote in the last election?	No	0	vote
		Yes	1	
<b>Respectful of rights</b>				
B17	Do you experience discrimination on the basis of disability?	No	0	discrimination
		Yes	1	
<b>C – Services and support systems are inclusive and functioning effectively in communities</b>				
<b>Local services</b>				
C1	In general, how would you rate your health today?	Very good	1	health
		Good	2	
		Neither good nor poor	3	
		Poor	4	
		Very poor	5	
C2	On your last visit to a health care provider, to what extent are you satisfied with the level of respect you were treated with?	Not at all	1	hcp_respect
		A little	2	
		Moderately	3	
		Mostly	4	
		Completely	5	

C3	In the last 12 months, has there been a time when you needed health care but did not get that care?	Yes, I was unable to get the care I needed	1	healthcare_needed
		No, I got the care I needed	2	
		No need for health care in the past 12 months	3	
C4	In the last 12 months, has there been a time when you needed rehabilitation services, such as physical, occupational or speech therapy, but did not get those services?	Yes, I was unable to get the care I needed [→ answer C5-16]	1	rehab_needed
		No, I got the care I needed	2	
		No need for health care in the past 12 months	3	
<b>Which reasons explain why you did not get that rehabilitation service?</b>				
C5	Rehabilitation service too far away	No	0	norehab_far
		Yes	1	
C6	Could not afford the cost of the visit	No	0	norehab_cost
		Yes	1	
C7	No transport available	No	0	norehab_notrans
		Yes	1	
C8	Transport not accessible	No	0	norehab_access
		Yes	1	
C9	Could not afford the cost of transport	No	0	norehab_costtrans
		Yes	1	
C10	Were previous badly treated	No	0	norehab_treated
		Yes	1	
C11	Could not take time off work or had other commitments	No	0	norehab_work
		Yes	1	
C12	The rehabilitation service providers' drugs or equipment were inadequate	No	0	norehab_inadequate
		Yes	1	
C13	Did not know where to go	No	0	norehab_wheretogo
		Yes	1	
C14	Tried but were denied healthcare	No	0	norehab_denied
		Yes	1	
C15	Thought you were not sick enough	No	0	norehab_notsick
		Yes	1	
C16	Other	No	0	norehab_other
		Yes	1	



<b>Assistive devices</b>				
C17	Do you use any aids to help you get around such as cane, crutch, or wheelchair, or to help you with self-care such as grasping bars, hand, or arm brace?	Yes, it works well	1	device
		Yes, but it doesn't work or isn't appropriate	2	
		No, but I need it	3	
		No, it's broken or not appropriate	4	
		No, I don't need it	5	

## **APPENDIX B: FOCUS GROUP SCHEDULE**

### **1. Communities are inclusive of all people with disabilities**

1. How would your community need to change if disabled people are to have more control over their lives?
2. Discuss participation of disabled people in cultural, religious and recreational activities in your community, including barriers and facilitators.
3. What would need to change in your community for disabled people to be better represented in leadership and authority roles?
4. Does disability-based discrimination take place in your community? If yes, describe how it operates, and what in the community would need to change in order to address the situation.
5. What forms of support would the families of disabled people in your community most benefit from?
6. Discuss the question of disabled persons' inclusion in spousal and sexual relationships in your community (Probe: In your community does a disability limit opportunities for sexual relationships?)

### **2. Services and support systems are inclusive and functioning effectively in communities**

1. Discuss key issues in your community surrounding disabled persons' access to:
  - (a) health services
  - (b) education, and
  - (c) livelihood opportunities.
2. Discuss issues regarding disability inclusion in regional and national development policies.
3. Describe the availability and accessibility of the following services in your community:
  - (a) transport
  - (b) appropriate housing
  - (c) adequate disability-related assistance with activities of daily living (dressing, bathing, eating and mobility)
  - (d) clean water and sanitation, and
  - (e) electricity.

## **APPENDIX C: CONSENT FORM – SURVEY**

This consent form comprises two sections:

Part 1: Information Sheet

Part 2: Certificate of Consent

### **Part 1: Information Sheet**

#### **Introduction**

My name is \_\_\_\_\_, working for the University of Cape Town in South Africa.

We are carrying out a research evaluation of the CBID programme in your country. I am going to give you information and invite you to be part of this research. This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me.

#### **Purpose**

The purpose of the study is to determine the effectiveness of the CBID programmes in your country and how you have been able to participate in the programme.

#### **Type of research intervention**

This research will involve your participation in an individual interview that will take about half an hour.

#### **Voluntary participation**

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. The choice that you make will have no bearing on your job or on any work-related evaluations or reports. You may change your mind later and stop participating, even if you agreed earlier.

#### **Duration**

The research takes place over one session in total. During that time, we will conduct one interview of approximately 30 minutes.

#### **Risks**

We are asking you to share with us some personal and confidential information about your views, opinions and experiences around the CBID programmes. You do not have to answer any question or take part in the interview if you don't wish to do so, and that is also fine. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview.

#### **Benefits**

There will be no direct benefit to you, but your participation is likely to help us gain a better understanding of the effectiveness of the CBID programme in your country.

## **Reimbursements**

You will not be provided any incentive to take part in the research.

## **Confidentiality**

We will not be sharing information about you to anyone outside of the research team. The information that we collect from this research project will be kept private. Any information about you will have a number on it instead of your name. Only the researchers will know what your number is and we will lock that information up with a lock and key or store it on a computer with a secure password. It will not be shared with or given to anyone.

## **Sharing the results**

Nothing that you tell us today will be shared with anybody outside the research team, and nothing will be attributed to you by name. The knowledge that we get from this research will be shared with you and your community before it is made widely available to the public.

## **Right to refuse or withdraw**

You do not have to take part in this research if you do not wish to do so, and choosing to participate will not affect your job or job-related evaluations in any way. You may stop participating in the interview at any time that you wish without your job being affected. I will give you an opportunity at the end of the interview to review your remarks, and you can ask to modify or remove portions of those, if you do not agree with my notes or if I did not understand you correctly.

## **Who to contact**

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact any of the following:

### **Contact details:**

Dr Judith McKenzie: Principal Investigator  
Head of Division  
Disability Studies  
Department of Health & Rehabilitation Sciences  
Faculty of Health Sciences  
University of Cape Town  
Email: [Judith.mckenzie@uct.ac.za](mailto:Judith.mckenzie@uct.ac.za)  
Telephone: +27 (0)21 406 6318  
Fax: +27 (0)21 406 6323

Professor Marc Blockman of the UCT FHS Human Research Ethics Committee can be contacted on +27 (0)21 406 6338 in case participants have any questions regarding their rights and welfare as research subjects on the study

## Part 2: Certificate of Consent

I have been invited to participate in the evaluation research on the effectiveness of the CBID programme.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

Print name of participant \_\_\_\_\_

Signature of participant \_\_\_\_\_

Date \_\_\_\_\_  
(DD/MM/YYYY)

### ***Statement by the researcher/person taking consent:***

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

1. An interview will be conducted.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Print name of researcher/  
person taking consent \_\_\_\_\_

Signature of researcher/  
person taking consent \_\_\_\_\_

Date \_\_\_\_\_  
(DD/MM/YYYY)

## **APPENDIX D: CONSENT FORM – FOCUS GROUP**

This consent form comprises two sections:

Part 1: Information Sheet

Part 2: Certificate of Consent

### **Part 1: Information Sheet**

#### **Introduction**

My name is \_\_\_\_\_, working for the University of Cape Town in South Africa.

We are carrying out a research evaluation of the CBID programme in your country. I am going to give you information and invite you to be part of this research. This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me.

#### **Purpose**

The purpose of the study is to determine the effectiveness of the CBID programmes in your country and how you have been able to participate in the programme.

#### **Type of research intervention**

This research will involve your participation in a focus group discussion that will take about an hour.

#### **Voluntary participation**

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. The choice that you make will have no bearing on your job or on any work-related evaluations or reports. You may change your mind later and stop participating even if you agreed earlier.

#### **Duration**

The research takes place over one session in total. During that time, we will conduct one focus group discussion of approximately 60 minutes.

#### **Risks**

We are asking you to share with us some personal and confidential information about your views, opinions and experiences around the CBID programmes. You do not have to answer any question or take part in the interview if you don't wish to do so, and that is also fine. You do not have to give us any reason for not responding to any question, or for refusing to take part in the discussion.

#### **Benefits**

There will be no direct benefit to you, but your participation is likely to help us gain a better understanding of the effectiveness of the CBID programme in your country.

## **Reimbursements**

You will not be provided any incentive to take part in the research.

## **Confidentiality**

We will not be sharing information about you to anyone outside of the research team. The information that we collect from this research project will be kept private. Any information about you will have a number on it instead of your name. Only the researchers will know what your number is and we will lock that information up with a lock and key or store it on a computer with a secure password. It will not be shared with or given to anyone.

## **Sharing the results**

Nothing that you tell us today will be shared with anybody outside the research team, and nothing will be attributed to you by name. The knowledge that we get from this research will be shared with you and your community before it is made widely available to the public.

## **Right to refuse or withdraw**

You do not have to take part in this research if you do not wish to do so, and choosing to participate will not affect your job or job-related evaluations in any way. You may stop participating in the interview at any time that you wish without your job being affected. I will give you an opportunity at the end of the interview to review your remarks, and you can ask to modify or remove portions of those, if you do not agree with my notes or if I did not understand you correctly.

## **Who to contact**

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact any of the following:

### **Contact details:**

Dr Judith McKenzie: Principal Investigator  
Head of Division  
Disability Studies  
Department of Health & Rehabilitation Sciences  
Faculty of Health Sciences  
University of Cape Town  
Email: [Judith.mckenzie@uct.ac.za](mailto:Judith.mckenzie@uct.ac.za)  
Telephone: +27 (0)21 406 6318  
Fax: +27 (0)21 406 6323

Professor Marc Blockman of the UCT FHS Human Research Ethics Committee can be contacted on +27 (0)21 406 6338 in case participants have any questions regarding their rights and welfare as research subjects on the study.

## Part 2: Certificate of Consent

I have been invited to participate in the evaluation research on the effectiveness of the CBID programme.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

Print name of participant \_\_\_\_\_

Signature of participant \_\_\_\_\_

Date \_\_\_\_\_  
(DD/MM/YYYY)

### ***Statement by the researcher/person taking consent:***

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

1. A focus group discussion will be conducted

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Print name of researcher/  
person taking consent \_\_\_\_\_

Signature of researcher/  
person taking consent \_\_\_\_\_

Date \_\_\_\_\_  
(DD/MM/YYYY)