

# Capturing the difference we make

## Community-based Rehabilitation Indicators Manual



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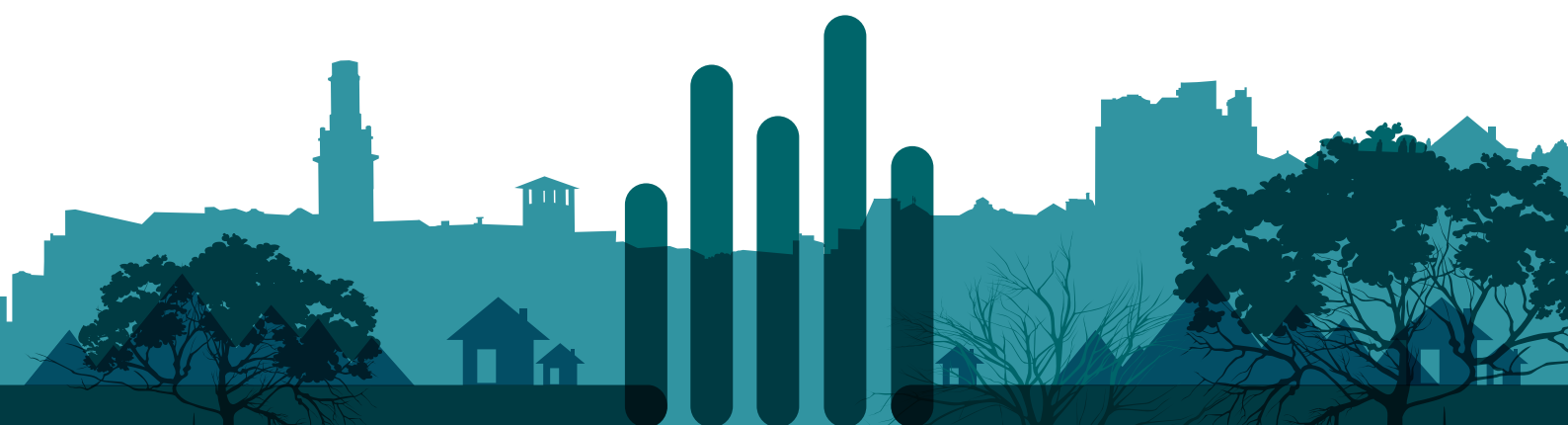
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# Capturing the difference we make

Community-based Rehabilitation Indicators Manual



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# ABBREVIATIONS

<b>CBR</b>	Community-based rehabilitation
<b>CRPD</b>	Convention on the rights of people with disability
<b>DPO</b>	Disabled people's organization
<b>IDDC</b>	International Disability and Development Consortium
<b>MDS</b>	Model disability survey
<b>NGO</b>	Nongovernmental organization
<b>WHO</b>	World Health Organization



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# BACKGROUND

Community-based Rehabilitation (CBR) has evolved over the past few decades as a fundamental component of community development, implemented in over 100 countries worldwide. CBR was initially a strategy to increase access to rehabilitation services in resource-constrained settings, but is now a multisectoral approach working to equalize opportunities and social inclusion of people with disability while combating the perpetual cycle of poverty and disability. However, CBR has long lacked a strong evidence base, hindered in part by the absence of standardized indicators. This manual addresses these needs and responds to the call of the *WHO Global Disability Action Plan 2014–2021* to “strengthen collection of relevant and internationally comparable data on disability and support research on disability and related services.”

WHO and the International Disability and Development Consortium (IDDC) have worked together to develop the indicators presented in this manual that capture the difference CBR makes in the lives of people with disability in the communities where it is implemented. This manual presents these (base and supplementary) indicators and provides simple guidance on collecting the data needed to inform them. The indicators have been developed to show the difference between people with disability and their families and those without disability in relation to the information reported in the indicators. This comparability provides valuable information to CBR managers, donors and government agencies alike, which can be used to guide decision-making, support advocacy and improve accountability. Further, the ability of the indicators to provide a comparison of the populations of people with disability to Persons without Disability aligns with the United Nations Convention on the Rights of People with Disability (CRPD), which states that people with disability have equal rights to those without disabilities.

The publication of this manual does not mean that the work on indicators by WHO, IDDC and the broader CBR community is complete. Indicators that capture the difference CBR makes in terms of affecting the social, administrative and attitudinal environment will be developed based on a collective and evidence-based process. Users of this manual are called to be active participants in strengthening the monitoring and evaluation of CBR by sharing data and experiences with WHO and the CBR community, ensuring ongoing development for years to come.



# **INTRODUCTION**

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## **What is contained in this manual?**

This manual contains indicators capable of capturing the situation of people with disability who live in a community where CBR is implemented. It provides a simple, brief and intuitive guide to selecting appropriate indicators and collecting data to inform them. Additional information is also provided on how to manage this data, including calculating percentages, displaying results and generating meaningful conclusions.

## **The purpose of CBR indicators**

This manual serves to standardize the monitoring of the situation of people with disability and their families, making it possible to track change over time and compare the difference CBR makes across areas and countries. This manual aligns with the *WHO Global Disability Action Plan 2014–2021*, and may also be used to monitor other development plans in an easy and efficient way.

## **What is the added value of CBR indicators?**

The indicators in this manual are the result of a collaborative, consensus-orientated and evidence-based effort by WHO, IDDC and the broader CBR community. They ensure comparability between CBR strategies in different countries and areas, and provide a means of monitoring over time through repeated data collection, which allows for informed decision-making, advocacy and accountability.

## **Collecting and using data**

This manual proposes a simple and flexible data collection strategy that can be customized to inform the desired indicators. Data collection is made easy and more efficient with an intuitive Android application (app) that is free to download. The app can be used to send data to oneself using the 'Send to Email' button, which will generate an excel of the data collected and send it to a desired email address, or it can be sent to the WHO Data Collection Platform, where graphs can be generated with this data (follow the instructions on the WHO CBR website).

## **Who should use the CBR indicators and when?**

The indicators can be used by CBR managers, CBR workers, researchers, funding agencies and/or any other interested bodies at any stage of CBR implementation. They can assess the current situation and monitor the difference CBR is making in the lives of people with disability in the areas where it is implemented. Annex 1 shows the context of the indicators in regards to what they capture, and Annex 8, Using Data to Inform the Indicators, and Annex 10, Case Studies, provide information how to use the information to deduce meaningful conclusions and instigate change.

## **Next steps**

The indicators in this manual concentrate on the perspective of the individual and household; however, work is currently starting that will expand these to capture CBR impact on social, administrative and attitudinal levels.

Real-life case studies on the use of the CBR indicators are needed to accompany subsequent versions of this manual in order to personalize and demonstrate the use of the indicators. As the manual will be available as an online resource, real-life case studies can be added as they become available.



# INDICATORS AT A GLANCE

## GOALS OF THE INDICATORS

The indicators have two **goals**:

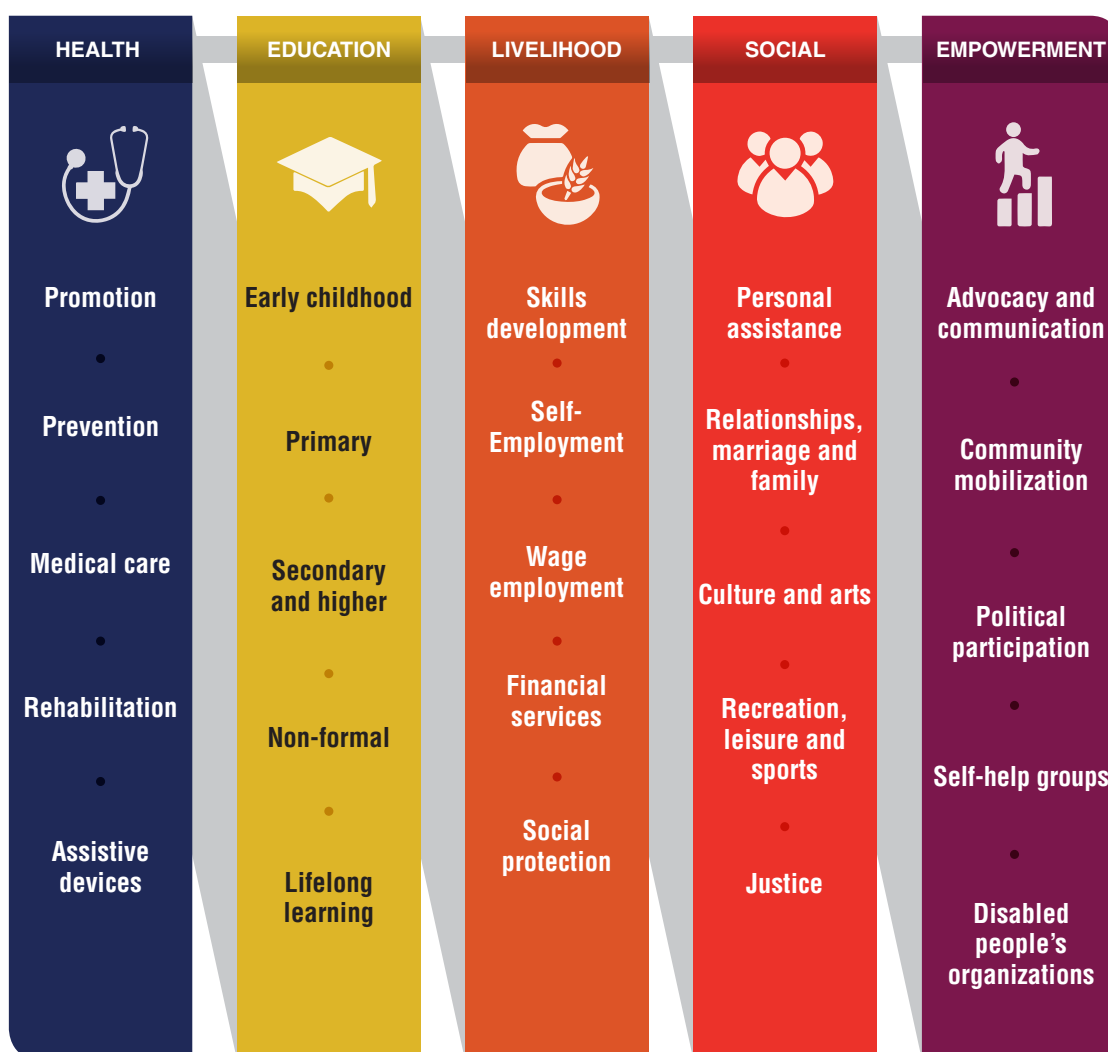
**Capturing the situation** of people with disability in the communities where CBR is implemented;

**Capturing differences** between adults, youth and children with disability, and those without disability in the areas of health, education, social life, livelihood and empowerment.

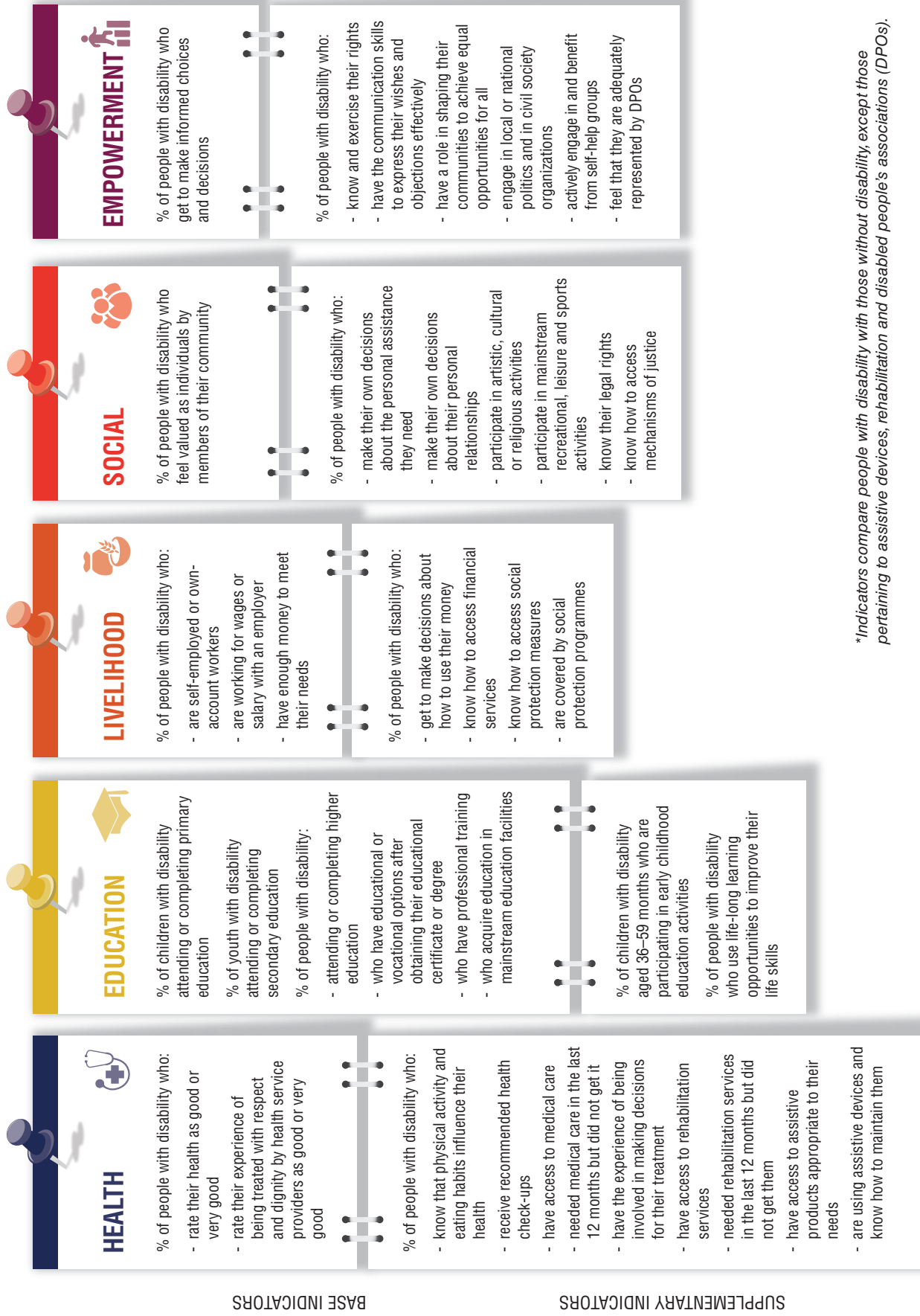
## BASE AND SUPPLEMENTARY CBR INDICATORS

All indicators are derived from the **CBR desirable outcomes** outlined in the CBR Guidelines (<http://www.who.int/disabilities/cbr/guidelines/en/>), and correspond to the components of the CBR matrix (health, education, livelihood, social and empowerment) and each of their five sub-elements, as seen in Figure 1.

**Figure 1. Components and elements of the CBR matrix**



**Figure 2. Base and supplementary indicators of each component of the CBR matrix**



*\*Indicators compare people with disability with those without disability, except those pertaining to assistive devices, rehabilitation and disabled people's associations (DPOs).*

This manual includes 40 base and supplementary indicators:

There are 13 base CBR indicators: health (2); education (6); livelihood (3); social (1); and empowerment (1). Base CBR indicators are broad enough to capture the difference CBR makes in the lives of people with disability, independent of specific CBR activities carried out in the community. For comparability among settings, countries, and over time, WHO recommends these 13 base CBR indicators be consistently included in all monitoring and evaluation procedures.

There are 27 supplementary CBR indicators (see Figure 2) that provide more specific coverage of the elements of the CBR components. From these users may select those that match the specific CBR goals and strategies of the community.



## DATA TO INFORM CBR INDICATORS

**Data** to inform base and supplementary CBR indicators could potentially be derived from different sources, such as censuses and surveys.

However, users may encounter challenges when drawing information from different sources. Firstly data from other sources (e.g. censuses) can only be used if questions identifying people with disability have been incorporated. Secondly, the information collected needs to align with and be capable of informing the CBR indicators.

**In light of these challenges, this manual provides a set of questions** explained in the following pages and comprehensively detailed (in Annex 7), which can be used to efficiently inform the indicators.

**Eight questions** are available for the **base CBR indicators** and **30** for the **supplementary indicators**. A detailed **interviewer question-by-question guide** can be found in Annex 7.

An **Android app for mobile phones** has been developed. This includes the questions to make data collection easier and more efficient. The app can be used to send data to oneself using the 'Send to Email' button, which will generate an excel of the data collected and send it to a desired email address, or it can be sent to the WHO Data Collection Platform, where graphs can be generated with this data (follow the instructions on the WHO CBR website). (see Annex 5).

## SURVEY

The questions can be compiled in a questionnaire and delivered in a survey. In this case the survey needs to be conducted in the **community where CBR is being implemented** and include people with disability and people without disability, independently of whether or not they participate in CBR.

The sample should include **all men, women, boys and girls with disability** in the community. Where the person with a disability cannot answer the questions themselves, a proxy, such as a family member, can answer on their behalf. For the sake of comparability, it is important to always document the approach or criteria used to identify people with disability.

A comparison group that includes **a similar number of men, women, boys and girls without disability** in the same community should also be included in the survey.

When the survey is undertaken for research purposes, more advanced methodological criteria need to be fulfilled.

Data collected with the android app will be shown in an excel sheet presented as percentages **comparing men, women, boys and girls with disability and those without disability** in the same community where CBR is implemented. Data is furthermore **broken down by gender and age**. Annex 8 describes how to calculate percentages, Annex 9 shows how to generate visual representations of the information, and Annex 10 demonstrates how information can be used to instigate change in different scenarios.





# CBR Indicators: OVERVIEW OF DESIRABLE OUTCOMES, INDICATORS AND QUESTIONS

HEALTH			
Element	Rephrased desirable outcome	Indicator	Question
General health	Men, women, boys and girls with disability equally access health services and engage in activities needed to achieve the highest attainable standard of health	% of people with disability who rate their health as good or very good compared to people without disability	In general, how would you rate your health today? 1=Very good; 2=Good; 3=Neither poor nor good; 4=Poor; 5=Very poor
General health	Men, women, boys and girls with disability feel they are respected and treated with dignity when receiving health services	% of people with disability who rate their experience of being treated with respect and dignity by health service providers as good or very good compared to people without disability	On your last visit to a health-care provider, to what extent are you satisfied with the level of respect you were treated with? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Promotion	Men, women, boys and girls with disability know how to achieve good levels of health and participate in activities contributing to their health	% of people with disability and their families that know that physical activity and eating habits influence their health compared to people without disability	Has your (doctor, CBR worker or any other health professional) ever discussed with you the benefits of eating a healthy diet, engaging in regular physical exercise or not smoking? 1=Yes; 2=No
Prevention	Men, women, boys and girls with disability participate in activities that prevent them and future generations from getting ill	% of people with disability who receive recommended health check-ups compared to people without disability	When was the last time you had a regular health check-up? 1=In the last year; 2=Between 1–2 years ago; 3=Between 2–5 years ago; 4=Longer than 5 years ago; 5=Never
Medical care	Men, women, boys and girls with disability access and benefit from quality medical services appropriate to their life-stage needs and priorities	% of people with disability that needed medical care in the last 12 months and did not get the care they need compared to people without disability	In the last 12 months, has there been a time when you needed health care but did not get that care? 1=Yes, I was unable to get the care I needed; 2=No, I got the care I needed; 3=No need for health care in the past 12 months

## HEALTH

Element	Rephrased desirable outcome	Indicator	Question
Medical care		% of people with disability that have access to medical care compared to people without disability	Which reason(s) explain(s) why you did not get health care? 1=Health-care facility too far away; 2=Could not afford the cost of the visit; 3=No transport available; 4=Transport not accessible; 5=Could not afford the cost of transport; 6=Were previously badly treated; 7=Could not take time off work or had other commitments; 8=Health-care provider's drugs or equipment were inadequate; 9=Health-care provider's skills were inadequate; 10=Did not know where to go; 11=Tried but were denied health care; 12=Thought you were not sick enough; 13=Other
Medical care		% of people with disability that have the experience of being involved in making decisions for their treatment compared to people without disability	On your last visit to a health-care provider, to what extent were you involved in making decisions for your treatment? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Rehabilitation	Men, women, boys and girls with disability engage in planning and carry out rehabilitation activities with the required services	% of people with disability that needed rehabilitation services in the last 12 months and did not get the services they need	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? 1=Yes, I was unable to get the care I needed; 2=No, I got the care I needed; 3= No need for rehabilitation services in the past 12 months
Rehabilitation		% of people with disability that have access to rehabilitation services	Which reason(s) explain(s) why you did not get that rehabilitation service? 1=Rehabilitation facility too far away; 2=Could not afford the cost of the visit; 3=No transport available; 4=Transport not accessible; 5=Could not afford the cost of transport; 6=Were previously badly treated; 7=Could not take time off work or had other commitments; 8=The rehabilitation service provider's drugs or equipment were inadequate; 9=The rehabilitation service provider's skills were inadequate; 10=Did not know where to go; 11=Tried but were denied health care; 12=Thought you were not sick enough; 13=Other





HEALTH			
Element	Rephrased desirable outcome	Indicator	Question
Assistive devices	Men, women, boys and girls with disability have access to, use, and know how to maintain appropriate assistive products in their daily life	% of people with disability that have access to assistive products appropriate to their needs	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? 1=Yes, and it works well; 2=Yes, but it doesn't work or isn't appropriate; 3=No, but I need it; 4=No, because it's broken or not appropriate; 5=No, I don't need it
Assistive devices			Do you use any visual aids, such as glasses or a white cane? 1=Yes, and it works well; 2=Yes, but it doesn't work or isn't appropriate; 3=No, but I need it; 4=No, because it's broken or not appropriate; 5=No, I don't need it
Assistive devices			Do you use anything to help you hear or communicate better? 1=Yes, and it works well; 2=Yes, but it doesn't work or isn't appropriate; 3=No, but I need it; 4=No, because it's broken or not appropriate; 5=No, I don't need it
Assistive devices		% of people with disability using assistive devices that know how to maintain them	Do you know how to keep your assistive device in good working condition? 1=Yes; 2=No

EDUCATION			
Element	Rephrased desirable outcomes	Indicator	Question
General education	<p>Policies and resources are conducive to education for people with disability and ensure smooth transitions through different stages of learning</p> <p>Children with disability participate in and complete quality primary education in an enabling and supportive environment</p> <p>Men, women, boys and girls with disability have resources and support to enrol and complete quality secondary and higher education in an enabling and supportive environment</p> <p>Youth with disability experience post-school options on an equal basis with their peers</p>	<p>% of children with disability who are attending or have completed primary education compared to children without disability</p> <p>% of youth with disability who are attending or have completed secondary education compared to youth without disability</p> <p>% of people with disability that are attending or have completed higher education compared to people without disability</p> <p>% of people with disability who have educational or vocational options after obtaining their educational certificate or degree compared to people without disability</p> <p>% of people with disability who have professional training compared to people without disability</p>	<p>What is the highest level of education you have obtained? (in order to align it to what is stated in the manual).</p> <p>Also might be good to add the option “middle school”, and to re-order the options logically, as follows:</p> <p>1=No schooling or never completed any grade  2=Elementary education  3=Middle School  4=Secondary School  5=Vocational education  6=College  7=University  8=Post-graduate studies  9=Professional training  10=Other</p>
General education		<p>% of people with disability who acquire education in mainstream education facilities compared to people without disability</p>	<p>Where did/do you receive your education?</p> <p>1=Regular institutions; 2=Specialized institutions; 3=Home-schooling; 4=Other forms of education</p>
Early childhood	<p>Children with disability actively participate in early childhood developmental activities and play, either in a formal or informal environment</p>	<p>% of children with disability age 36–59 months who are participating in early childhood education activities compared to children without disability aged 36–59 months</p>	<p>Does [NAME] attend any organized learning or early childhood education program, whether at a private or government facility, including kindergarten or community child care?</p> <p>1=Yes; 2=No</p>





EDUCATION			
Element	Rephrased desirable outcomes	Indicator	Question
Non-formal education	Children and youth with disability participate in a variety of non-formal learning opportunities based on their needs and desires.	For children: % of those who select response option 3 or 4 in response to the question in Education in general, "Where did/do you receive your education?" compared to children without disability who selected the same response options. For adults: % of those who responded "yes" to the question in Lifelong learning "Do you participate in learning opportunities to improve your skills for everyday life or work?" compared to people without disability who answered "yes" to the same question.	Where did/do you receive your education? 1=Regular institutions; 2=Specialized institutions; 3=Home-schooling; 4=Other forms of education  Do you participate in learning opportunities to improve your skills for everyday life or work? 1=Yes; 2=No
Lifelong learning	Men, women, boys and girls with disability make use of youth or adult-centred learning opportunities to improve their life skills and living conditions	% of people with disability who use life-long learning opportunities to improve their life skills compared to people without disability	Do you participate in learning opportunities to improve your skills for everyday life or work? 1= Yes; 2=No
Lifelong learning	Men, women, boys and girls with disability experience equal opportunities to participate in learning opportunities that meet their needs and respect their rights		To what extent does it fit your needs? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely

## LIVELIHOOD

Element	Rephrased desirable outcomes	Indicator	Question
General livelihood	Men and women with disability have paid and decent work in the formal and informal sector on an equal basis with others  Women and men with disability earn income through their own chosen economic activities  Youth and adults with disability acquire marketable skills on an equal basis with others through a range of inclusive training opportunities	% of people with disability who are self-employed or own-account workers compared to people without disability  % of people with disability who are working for wages or salary with an employer compared to people without disability	What is your current working situation? 1=Not working for wages and not looking for paid work; 2=Not working and not looking for work; 3=Working for wages or salary with an employer (full- or part-time); 4=Working for wages, but currently on sick leave for more than 3 months; 5=Self-employed or own-account worker; 6=Working as unpaid family member (e.g. working in family business); 7=Retired because of the health condition; 8=Retired because of age; 9=Early retirement; 10=Other
General livelihood		% of people with disability who have enough money to meet their needs compared to people without disability	Do you have enough money to meet your needs? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
General livelihood	Women and men have control over the money they earn	% of people with disability who get to make decisions about how to use his/her money compared to people without disability	Do you get to decide how to use your money? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Financial services	Men and women with disability have access to grants, loans and other financial services on an equal basis with others	% of people with disability who know how to access financial services compared to people without disability	Do you know how to get financial services such as credit, insurance, grants, savings programmes? 1=Yes; 2=No
Social protection	Men and women with disability access formal and informal social protection measures they need	% of people with disability who know how to access social protection measures	Do you know how to get social protection against loss of income through old age, sickness or disability? 1=Yes; 2=No
Social protection		% of people with disability who are covered by social protection programmes compared to people without disability	Do you currently benefit from any social protection programme, such as loss of income through old age, sickness or disability? 1=Yes; 2=No



## SOCIAL

Element	Rephrased desirable outcomes	Indicator	Question
General social	Men, women, boys and girls with disability feel valued as community members and have a variety of social identities, roles and responsibilities	% of people with disability that feel valued as individuals by members of their community compared to people without disability	Do you feel that other people respect you? For example, do you feel that others value you as a person and listen to what you have to say? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Personal assistance	Men, women, boys and girls with disability access and control the way needed personal assistance is provided	% of people with disability who get to make their own decisions about the personal assistance they need	Do you get to make decisions about the personal assistance that you need (who assists you, what type of assistance, when to get assistance)? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Relationships, marriage, and family	Men, women, boys and girls with disability experience support of the community and their families to socialize and form age-appropriate and respectful relationships	% of people with disability who get to make their own decisions about their personal relationships compared to people without disability	Do you get to make your own decisions about your personal relationships, such as friends and family? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Culture and arts	Men, women, boys and girls with disability participate in artistic, cultural or religious events in and outside their home as they choose	% of people with disability who get to participate in artistic, cultural or religious activities compared to people without disability	Do you get to participate in artistic, cultural or religious activities? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Recreation, leisure, and sports	Men, women, boys and girls with disability participate in inclusive or specific recreation, leisure and sports activities	% of people with disability who get to participate in mainstream recreational, leisure and sports activities compared to people without disability	Do you get to participate in community recreational, leisure and sports activities? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Justice	All people with disability are recognized as equal citizens with legal capacity	% of people with disability who know their legal rights compared to people without disability	To what extent do you know your legal rights? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Justice	People with disability access and use formal and informal mechanisms of justice	% of people with disability who know how to access mechanisms of justice compared to people without disability	Do you know how to access the justice system? 1=Yes; 2=No

## EMPOWERMENT

Element	Desirable outcomes	Indicator	Question
General empowerment	People with disability make informed choices and decisions	% of people with disability who get to make informed choices and decisions compared to people without disability	Do you get to make the big decisions in your life? For example, deciding who to live with, where to live, or how to spend your money? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
General empowerment	People with disability advocate for and/or exercise their rights	% of people with disability who know and exercise their rights compared to people without disability	Do you think that the policies in your country provide people with disability equal rights as other people? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Advocacy and communication	Men, women, boys and girls with disability effectively use communication skills and resources (including supportive decision-making) to facilitate interactions and influence change	% of people with disability who have the communication skills to express their wishes and objections effectively compared to people without disability	Are you satisfied with your ability to persuade people of your views and interests? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Community mobilization	Men, women, boys and girls with disability play a catalysing role in mobilizing key community stakeholders to create an enabling environment	% of people with disability who have a role in shaping their communities to achieve equal opportunities for all compared to people without disability	Do you get to influence the way your community is run? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Political participation	Men and women with disability participate in political processes on an equal basis with others	% of people with disability who engage in local or national politics and in civil society organizations compared to people without disability	Did you vote in the last election? 1=Yes; 2=No
Self-help groups	People with disability actively engage in and benefit from self-help groups in local communities, if they choose (inclusive or specific)	% of people with disability who actively engage in and benefit from self-help groups compared to people without disability	Are you a member of a self-help group? 1=Yes; 2=No, but I would like to; 3=No, I don't want to
Disabled People's Organizations	Men and women with different kinds of disability living in different situations (rural or urban areas, poor or rich, refugees) feel they are adequately represented by DPOs  DPOs are influential stakeholders in decision-making	% of people with disability who feel that they are adequately represented by DPOs	To what extent do you feel Disabled People's Organizations adequately represent your concerns and priorities? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely

# ANNEX 1:

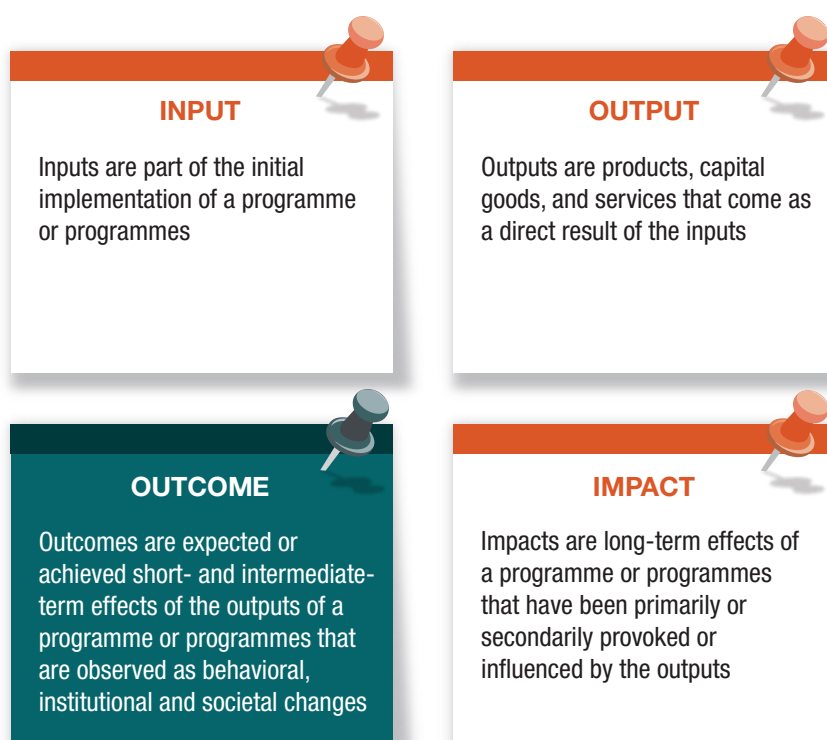
## CBR INDICATORS IN CONTEXT<sup>1</sup>

### What is an Indicator?

Indicators look to measure *the intended or unintended, positive or negative effects of one or more activities intended to contribute to physical, financial, institutional, social, environmental, or other benefits to a society, community, or group of people.*

There are four types of results which can be measured through the use of *indicators*:

**Figure 3. The four types of results measured through the use of indicators**



**The indicators presented in this manual are outcome indicators (dark green box).**

Outcome indicators were selected for two reasons:

Input and output indicators do not provide an indication of the extent to which a program is achieving its goals. They only provide an indication that the programme or programmes are being implemented and how.

Impact indicators are long-term effects that are beyond attributions to a CBR intervention, as in some cases they may reflect societal change.

<sup>1</sup> This section is based on:

- Organisation for Economic Co-operation and Development. (2004). Glossary of Key Terms in Evaluation and Results Based Management. Paris: Organisation for Economic Co-operation and Development.
- Monitoring, evaluation and review of national health strategies: a country-led platform for information and accountability. World Health Organisation 2011.

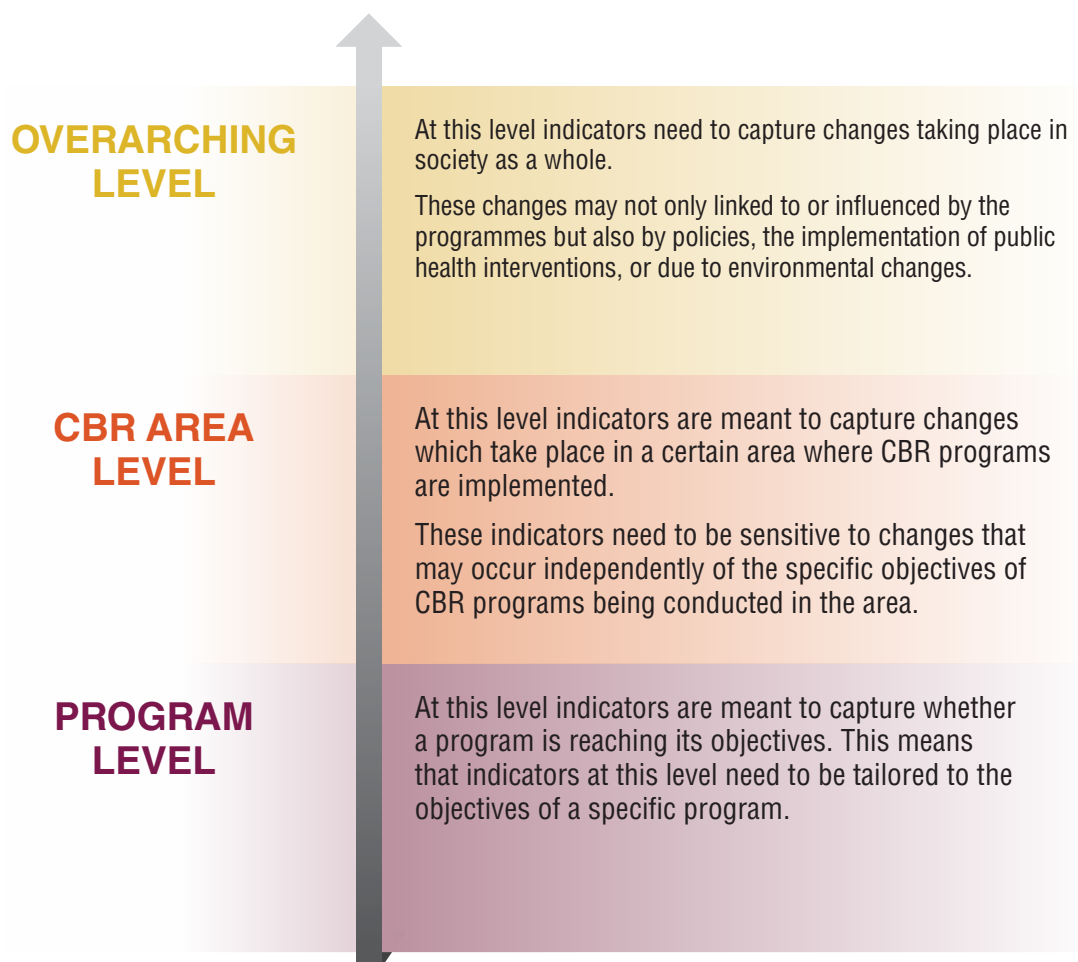


## Levels of monitoring

There are various levels from which one can observe the changes happening in the lives of people with disability.

This manual defines three levels at which CBR monitoring can take place:

**Figure 4. Three levels at which CBR monitoring can take place**



The lower the level of monitoring, the more specific the indicators have to be.

**The indicators presented in this manual are designed to capture the difference CBR makes at the CBR area level** rather than for specific CBR programmes. However, the indicators can still be used in communities where there is only one programme being implemented (as has been demonstrated in Case Study 3 of Annex 10).



## ANNEX 2:

# DEVELOPMENT OF THE CBR INDICATORS AND QUESTIONS TO INFORM THEM

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The development of the indicators and the questions to inform them was a collaborative effort by WHO and the IDDC CBR task force that took place in the following four phases.

### Phase one: Overview of previous work

The goal of the first phase was to gain in-depth knowledge of work previously done on CBR indicators and avoid repetition of work.

### Phase two: Rephrasing CBR desirable outcomes

For the sake of consistency with previous WHO work, the indicators presented in this manual are based on the desirable outcomes contained in the *CBR Guidelines* (<http://www.who.int/disability/cbr/guidelines/en/>). However, since the desirable outcomes were originally not formulated to serve as the basis of indicators, they needed to be rephrased. This was done in an iterative process of several rounds between WHO and the IDDC CBR task force.

### Phase three: Alpha-Version of CBR indicators

Using the updated CBR desirable outcomes as a starting point, WHO and the IDDC CBR task force undertook another iterative process to develop an initial set of 52 indicators, titled Alpha-Version. Questions to inform each of the Alpha-Version indicators were then proposed. In an effort to avoid duplicating existing work, whenever possible questions from existing surveys, such as the *Model Disability Survey* (<http://www.who.int/disability/data/mds/en/>) or the *WHO Study on Global Ageing and Adult Health* (SAGE; <http://www.who.int/healthinfo/sage/en/>) were used when possible.

### Phase four: Feasibility and validity testing

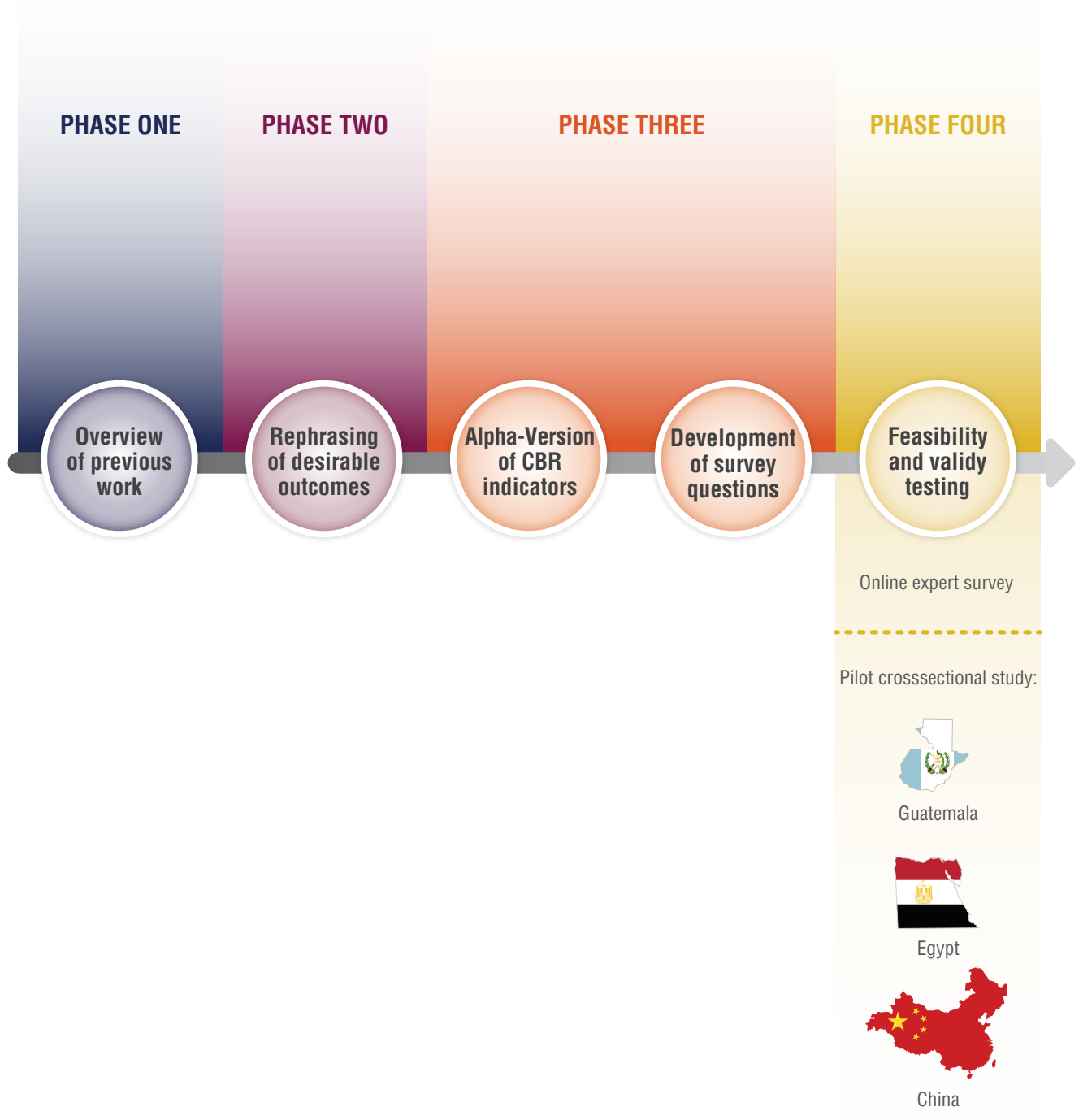
The feasibility and validity of the proposed indicators and questions were tested via two studies:

- 1) An **online expert** survey, in which CBR experts from varying backgrounds were requested to rank the indicators of each component and element by their relevance to CBR and to rate the face validity of the questions proposed to capture them.
- 2) A **pilot cross-sectional study** conducted in China, Egypt and Guatemala involving 801 participants with and without disability. The study was conducted using the questions proposed in Phase three and a first version of the Android app for data collection.

The compilation of results from 1) and 2) led to the selection of the set of **13 base** and **27 supplementary CBR indicators** that are presented in this manual.



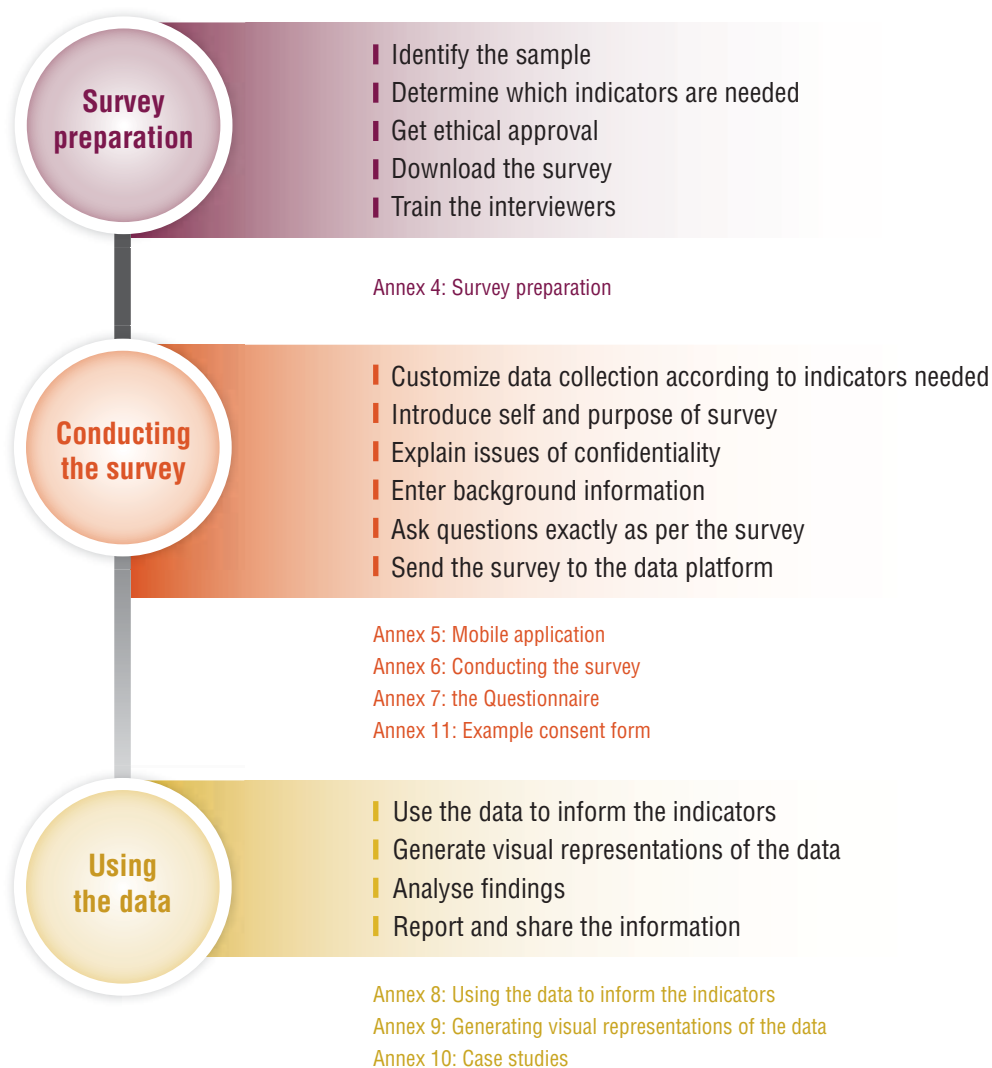
**Figure 5. Overview of the CBR Indicators Manual development process**



# ANNEX 3: CONDUCTING A SURVEY TO COLLECT THE INFORMATION NEEDED TO INFORM THE CBR INDICATORS

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**Figure 6. Summary of process of conducting a survey to collect information to inform indicators**



## ANNEX 4: SURVEY PREPARATION

This guide needs to be read if the data to inform the indicators will be collected using the questions presented in this manual. It is very important that people involved in data collection read this to get an in-depth understanding of how to prepare for the survey and collect the data.

INTERVIEWER GUIDE: SURVEY PREPARATION	
Steps	What should be done
Identify the sample to be interviewed within the community where CBR is implemented	<p>Two groups need to be approached for interviews:</p> <ol style="list-style-type: none"> <li>1) Adults and children <b>with disability</b>,<sup>2</sup> regardless of whether they are currently participating in CBR or not.</li> <li>2) Adults and children <b>without disability</b> living in the same community, so that a direct comparison between populations is possible.</li> </ol> <ul style="list-style-type: none"> <li>- In both groups, a <b>balanced sample</b> of men and women, boys and girls is recommended.</li> <li>- The groups of people with disability and people without disability are different, and in light of this <b>the specific approach or criteria used to categorize the groups should be consciously selected and documented.</b></li> <li>- When <b>determining the size of the sample</b>, consideration should be made for how strong the results need to be (generally the bigger the sample, the more reliable the findings are), the geographical size of the area in which the community resides, how much time is available, and the number of interviewers.</li> </ul>
Determine which indicators are needed	<p>WHO recommends <b>always using at least the questions that inform the base indicators.</b> What supplementary indicators are used will depend on the specific CBR strategies and goals in each community.</p> <ul style="list-style-type: none"> <li>- The length of an interview including questions for the base and supplementary indicators will depend on the final number of questions selected. An interview including all questions targeting base and supplementary indicators would take approximately 20 minutes.</li> </ul>
Get ethical approval for conducting the survey	<p>Ensure ethical approval is acquired according to the regulations of the country, region or institution.</p>

<sup>2</sup> The ICF definition of disability that was used in the WHO World report on disability should be used to determine who is classified as an adult or child with a disability: Disability is an umbrella term for impairments, activity limitations, and participation restrictions, and represents the outcome of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).



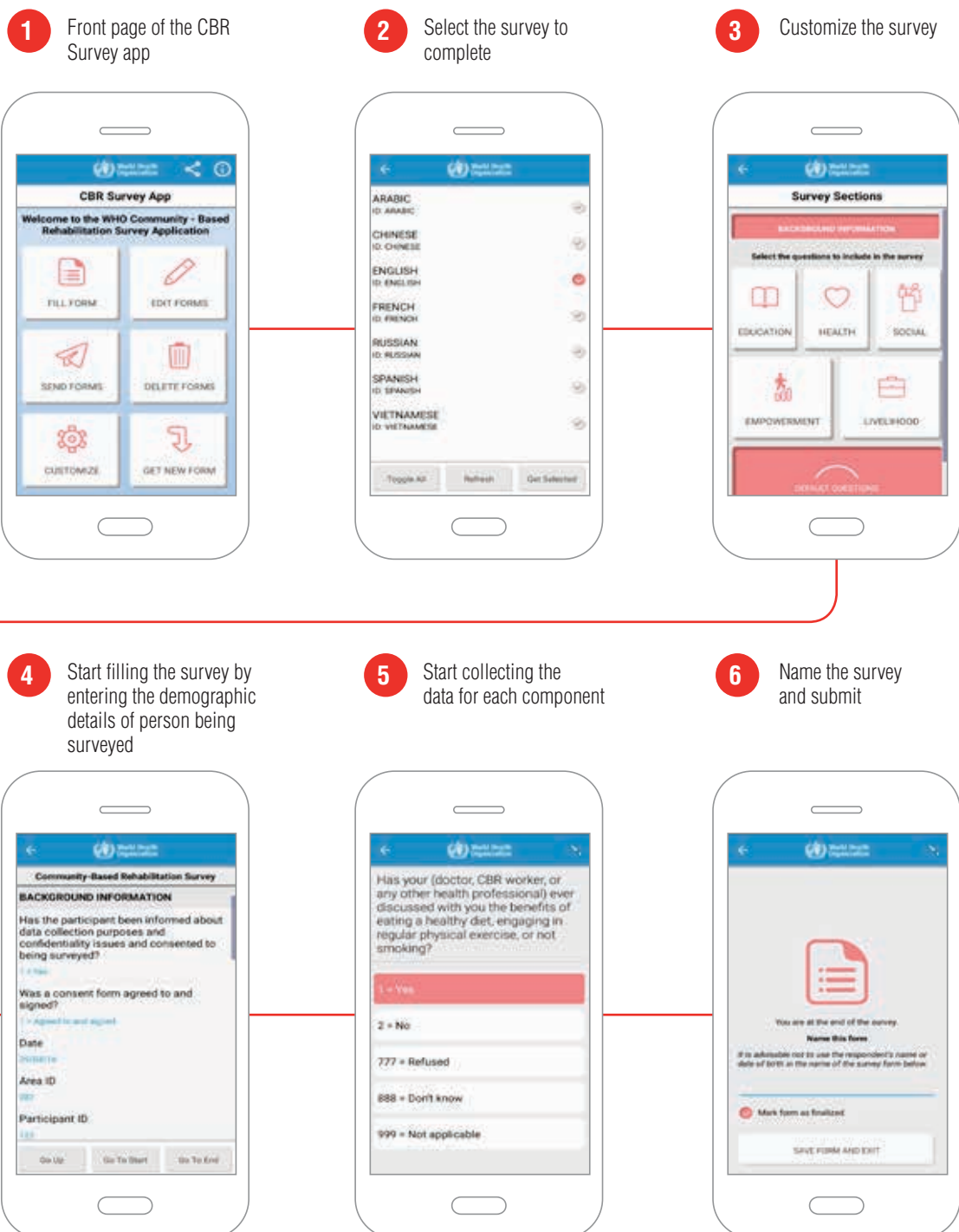
## ANNEX 4: SURVEY PREPARATION CONT

SURVEY PREPARATION	
Steps	What should be done
Confidentiality and mechanisms for follow up	<p><b>All data must be collected anonymously using a participant ID.</b></p> <p><b>For specific research purposes users may want to follow up the same population over time.</b> The participant ID can be manually linked to their details (name and contact information), which should be held securely by one person responsible for data collection. The information is strictly confidential and should only be used for the purpose of identifying participants for repeat surveys. The information collected and processes used to protect it need to be included in the application for ethical approval prior to conducting the survey (see 'Get ethical approval for conducting the survey').</p> <p>When repeating the survey, ensure that the same participant numbers are re-entered so the data can be linked.</p>
Download the mobile app or hard-copy of the survey	<p>An intuitive and easy to use <b>Android app for mobile</b> phones has been developed to collect data with the questions outlined in this manual.</p> <p><b>The mobile app...</b></p> <p><b>...can be downloaded</b> via the WHO CBR website (<a href="http://www.who.int/disability/cbr/en/">http://www.who.int/disability/cbr/en/</a>). A short video explaining how the app works can also be found on this page.</p> <p><b>... works offline;</b> an internet connection is only needed to download the app and the survey in the desired language via the 'Get new form' button, and to send in completed interviews when desired to an email address of your choice or WHO's Data Collection Platform.</p> <p>Alternatively, a <b>hard-copy version of the survey</b> is available on the WHO CBR website (<a href="http://www.who.int/disability/cbr/en/">http://www.who.int/disability/cbr/en/</a>). Questions relating to different groups of supplementary indicators can be downloaded separately. Data collected with hard-copy survey forms needs to be manually entered into a database, therefore the app provides a more efficient data collection approach and reduces the risk of data entry error.</p>
Train the interviewers	<p>All those conducting interviews should be familiar with this manual and the mobile app if this is being used. Consider running mock-interviews prior to conducting them with the sample.</p> <p>Issues of confidentiality and informed consent should be well understood by all interviewers.</p>
Automatically reviewing submitted data	<ul style="list-style-type: none"> <li>- Data is temporarily stored in the mobile phone, until the interviewer submits the completed interviews. Submitted interviews are emailed to either an email address or to the WHO's data platform.</li> <li>- The WHO CBR website will show the collected data about each indicator as graphics comparing people with disability with other members of the community, as well as comparing boys, girls, men and women.</li> </ul>
Customize data collection	<ul style="list-style-type: none"> <li>- The default option of the app includes all questions proposed for the 13 base CBR indicators. An interview including these questions will take approximately 5 minutes.</li> <li>- The app can be customized to include additional questions targeting supplementary CBR indicators.</li> </ul>
Introduce oneself and the reason for the interview	<p>A recommended introduction is:</p> <p><i>"The reason I am contacting you is because we want to better-understand how children and adults live in their communities, and about their health, education, and social life. For this, I would like to ask you a number of questions. Let me assure you that whatever information you tell us is completely confidential and will only be used anonymously."</i></p>



# ANNEX 5: MOBILE APPLICATION

**Figure 7. Using the mobile application**



The **app** can be downloaded at <http://www.who.int/disability/cbr/en/>. A short video explaining how the app works can also be found on this page.

The **app works offline**: An Internet connection is only needed to download the app as well as the survey itself (via the 'Get New Form' button), and to send the entered data when desired.

The **default questions section** of the app includes all questions targeting **base CBR indicators**. Collecting data with the default questions section will take approximately 5 minutes.

The **app can be customized** to include additional questions targeting **supplementary CBR indicators**. Collecting data with all questions for base and supplementary CBR indicators would take approximately 20 minutes to complete.

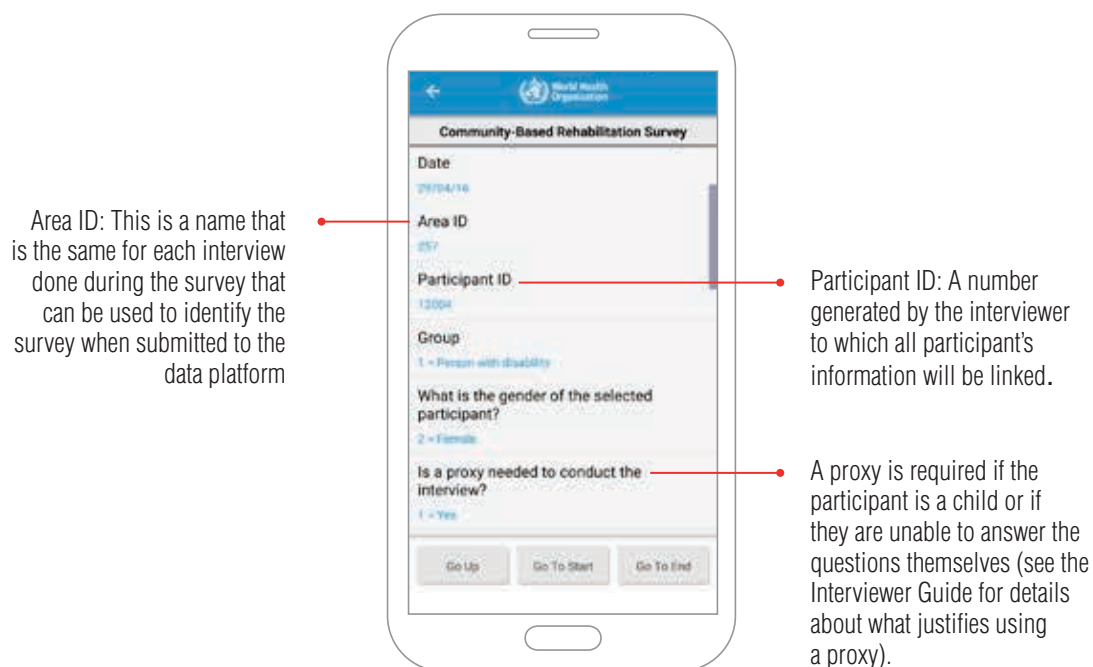
Data is entered anonymously and temporarily stored on the mobile phone until it is submitted, at which time it will be sent to the user or stored on the WHO Data Collection Platform (<https://beta.whodcp.org>).

Anyone using the app will have access to their own data. Instructions are available in the app itself and in the demonstration video, available via the WHO CBR website (<http://www.who.int/disability/cbr/en/>).

**Visual representations** of the collected data as **graphs** can be generated in the WHO Data Collection Platform.

Further visual **representations anonymously comparing data between countries and regions** will be presented on the WHO CBR website (<http://www.who.int/disability/cbr/en/>).

## Figure 8. Explanation of background information



## ANNEX 6: CONDUCTING THE SURVEY

THE INTERVIEW	
Steps	What should be done
<p><b>Explain issues of confidentiality and provide an estimate of how long the interview will take</b></p>	<p><b>Duration of interview</b> – The survey will take approximately 5 to 20 minutes, depending on how many questions are included. It is recommended to consider 30 seconds per question.</p> <p><b>Individual rights</b> – The respondent may decline to be interviewed, stop the interview at any point, or refuse to answer some questions.</p> <p><b>Confidentiality</b> – All data will be collected or reported anonymously. The app will prompt the interviewer to confirm whether or not informed consent was acquired from the participant before entering their background information <i>“Has the participant been informed about data collection purposes and confidentiality issues and consented to being surveyed? Yes/No.</i> If the answer is yes, the interviewer will be prompted by the app, <i>“Was a consent form agreed to and signed?”</i> If a consent form is not needed, select Not Applicable. An example of a consent form that may be used when conducting the survey can be found in Annex 11.</p>
<p><b>Read questions exactly as they are written on the screen</b></p>	<p>All questions appearing in <b>black</b> should be read out loud</p> <p>All questions appearing in <b>blue</b> should NOT be read out loud. If the participant has difficulty responding, then <b>blue</b> response options can be read out loud.</p> <p>Questions marked with an asterisk (*) imply that multiple response options can be selected.</p>
<p><b>Upon starting an interview, some questions will be presented to collect demographic information on the respondent. These questions SHOULD NOT be read out loud to the respondent.</b></p>	
<p><b>Date</b></p>	<p>The first question of the Background page of the app is to select the date.</p>
<p><b>Area ID</b></p>	<p>Provide an area name that will be used for all the interviews in the survey to identify the survey when submitted to the data platform.</p>
<p><b>Participant ID</b></p>	<p>Ensure that each participant has a unique ID. This may be achieved by providing each interviewer a pre-established list of ID numbers that they may draw from for each participant.</p>
<p><b>Group</b></p>	<p>If the respondent is a person with disability, select 1. If the respondent does not have a disability, select 2.</p>
<p><b>Record the gender of the selected participant</b></p>	<p>Record the respondent’s sex (male or female) based on observation in the Background section of the app.</p>
<p><b>Decide whether a proxy is needed to conduct the interview</b></p>	<p>Seeking a proxy is justified if a significant cognitive limitation, memory problem or health condition is present that would, in the interviewer’s opinion, be overly stressful for the respondent or provide responses of questionable accuracy.</p> <p>The app will prompt the interviewer to record the relationship of the proxy to the respondent; they could be the mother, father, grandparent, spouse, non-spouse or other.</p>
<p><b>Record the participant’s age</b></p>	<p>Enter the participant’s age in the Background page of the app.</p>



## ANNEX 6: CONDUCTING THE SURVEY CONT.

THE INTERVIEWER	
Steps	What should be done
<p><b>Probe if respondent has difficulties answering</b></p>	<p>If the respondent does not answer a question, it will be necessary to probe further to get an appropriate response. For instance, probing is required when the respondent:</p> <ul style="list-style-type: none"> <li>- misinterprets or does not understand the question</li> <li>- cannot make up his or her mind, or</li> <li>- says that they don't know the answer.</li> </ul> <p><b>Probing techniques include to:</b></p> <p><b>Repeat the question</b> – The respondent may come up with the answer if they hear the question a second time.</p> <p><b>Pause</b> – This gives the respondent time to collect their thoughts.</p> <p><b>Repeat the respondent's reply</b> – This is often an effective way of having the respondent reflect on the answer they have just given.</p> <p><b>Use neutral probes</b> – Never give the impression to approve or disapprove of what the respondent says, or that an answer is right or wrong. Instead, if more information is needed, ask "anything else?" or "could you tell me more about...?"</p>
<p><b>If probing does not lead to an answer, use the "Not applicable", "Don't know" or "Refuse" response options as appropriate</b></p>	<p><b>"Not applicable"</b> – Some questions may not apply or be relevant for the respondent. In this case, select this option.</p> <p><b>"Don't know"</b> – In general this response is NOT encouraged and should not be offered to the respondent. However, if the respondent is still not able to answer after probing, select this option.</p> <p><b>"Refuse"</b> – A respondent may refuse to answer certain questions. Before selecting this option, the interviewer should attempt to determine the reason for the refusal, and attempt to probe and get an answer.</p>



# ANNEX 7: THE QUESTIONNAIRE

Boxes shaded in grey denote those that inform base indicators.

<b>HEALTH COMPONENT</b>		
<p>This component includes general questions as well as questions tackling elements of health promotion, prevention, medical care, rehabilitation, and assistive devices. Some of the questions are derived from the Model Disability Survey (<a href="http://www.who.int/disability/data/mds/en/">http://www.who.int/disability/data/mds/en/</a>) and from the GALLUP Annual Consumption Habits Poll (<a href="http://www.gallup.com/poll/163772/americans-say-doctors-advise-health-habits.aspx">http://www.gallup.com/poll/163772/americans-say-doctors-advise-health-habits.aspx</a>). <b>Response options in blue must not be read aloud by the interviewer</b></p>		
<b>Item</b>	<b>Question and response options</b>	<b>Explanations</b>
<b>H01</b>	<p><b>In general, how would you rate your health today?</b> 1=Very good; 2=Good; 3=Neither poor nor good; 4=Poor; 5=Very poor</p>	Respondents should evaluate their general health including physical and mental health.
<b>H02</b>	<p><b>On your last visit to a health-care provider, to what extent were you satisfied with the level of respect you were treated with?</b> 1 (Not at all); 2; 3; 4; 5 (Completely)</p>	Respondent should rate how respectfully they were treated on their last visit to a health-care provider on a scale of 1 to 5, where 1 means not at all and 5 completely.
<b>H03</b>	<p><b>Has your (doctor, CBR worker, or any other health professional) ever discussed with you the benefits of eating a healthy diet, engaging in regular physical exercise, or not smoking?</b> 1=Yes; 2=No</p>	Respondent should reflect on whether any health professional has ever discussed any actions that prevent illness. This includes eating a healthy diet including fruits and vegetables, regular hand washing, exercising regularly, not smoking, among others.
<b>H04</b>	<p><b>When was the last time you had a regular health check-up?</b> 1=In the last year; 2=Between 1–2 years ago; 3=Between 2–5 years ago; 4=Longer than 5 years ago; 5=Never</p>	This refers to a medical visit meant to prevent getting sick or to identify a health condition in an early stage and does not mean to going to a doctor because of illness or for a disability-related problem.
<b>H05</b>	<p><b>In the last 12 months, has there been a time when you needed health care but did not get that care?</b> 1=Yes, I was unable to get the care I needed 2=No, I got the care I needed No; 3=No need for health care in the past 12 months</p>	Respondents should answer yes if they needed health care, but did not get it. They should answer no if they needed health care, but had no problems getting it. If the respondent did not need health care in the last 12 months then select the “No need for health care” option.
<b>H06</b>	<p><b>Which reason(s) explain(s) why you did not get health care?*</b> 1=Health-care facility too far away; 2=Could not afford the cost of the visit; 3=No transport available / accessible; 4=Transport not accessible; 5=Could not afford the cost of transport; 6=Were previously badly treated; 7=Could not take time off work or had other commitments; 8=Health-care provider’s drugs or equipment were inadequate; 9=Health-care provider’s skills were inadequate; 10=Did not know where to go; 11=Tried but were denied health care; 12=Thought you were not sick enough; 13=Other</p>	<p>If the respondent’s answer is not listed in the response options, select “Other”.</p> <p><b>Record all reasons what the respondent indicates.</b> The cost of visit (response option 2) can refer to the medical fees, transit costs or any others costs associated to the visit.</p>



This component includes general questions as well as questions tackling elements of health promotion, prevention, medical care, rehabilitation, and assistive devices. Some of the questions are derived from the Model Disability Survey (<http://www.who.int/disability/data/mds/en/>) and from the GALLUP Annual Consumption Habits Poll (<http://www.gallup.com/poll/163772/americans-say-doctors-advise-health-habits.aspx>). **Response options in blue must not be read aloud by the interviewer**

Item	Question and response options	Explanations
H07	<p><b>On your last visit to a health-care provider, to what extent were you involved in making decisions for your treatment?</b></p> <p>1 (Not at all); 2; 3; 4; 5 (Completely)</p>	Respondent should rate their experience of being involved in decisions about treatment in their last visit to a health-care provider, such as having treatment options explained or being asked which treatment they prefer using a scale from 1 to 5, where 1 means not at all and 5 completely.
H08	<p><b>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?</b></p> <p>1=Yes, I was unable to get the services I needed 2=No, I got the services I needed 3=No need for rehabilitation services in the past 12 months</p>	Respondents should answer “yes” if they needed rehabilitation services, but did not get them. They should answer “no” if they needed rehabilitation services, but had no problems getting them. If the respondent did not need rehabilitation services in the last 12 months then select the “No need for rehabilitation services” option.
H09	<p><b>Which reason(s) explain(s) why you did not get that rehabilitation service?*</b></p> <p>1=Rehabilitation facility too far away; 2=Could not afford the cost of the visit; 3=No transport available; 4=Transport not accessible; 5=Could not afford the cost of transport; 6=Were previously badly treated; 7=Could not take time off work or had other commitments; 8=The rehabilitation service provider’s drugs or equipment were inadequate; 9=The rehabilitation service provider’s skills were inadequate; 10=Did not know where to go; 11=Tried but were denied health care; 12=Thought you were not sick enough; 13=Other</p>	<p>The cost of visit (response option 2) can refer to medical fees, transit costs or any others costs associated with the visit.</p> <p>If the respondent’s answer is not listed in the response options, select “Other”.</p> <p><b>Record all reasons that the respondent indicates.</b></p>
H10	<p><b>Do you use any aids to help you get around such as a cane, crutch, or wheelchair; or to help you with self-care such as grasping bars, hand, or arm brace?</b></p> <p>1=Yes, and it works well; 2=Yes, but it doesn’t work or isn’t appropriate; 3=No, but I need it; 4=No, because it’s broken or not appropriate; 5=No, I don’t need it</p>	<p>Mobility aids are, for instance, a cane, crutch, wheelchair, walking frame, prosthesis or orthopedic device, among others.</p> <p>Aids for self-care are, for instance, hand braces, arm braces or grasping tools, among others.</p>
H11	<p><b>Do you use any visual aids, such as glasses or a white cane?</b></p> <p>1=Yes, and it works well; 2=Yes, but it doesn’t work or isn’t appropriate; 3=No, but I need it; 4=No, because it’s broken or not appropriate; 5=No, I don’t need it</p>	Visual aids are, for instance, glasses or books with large print, a white cane or guide dogs, among others.
H12	<p><b>Do you use anything to help you hear or communicate better?</b></p> <p>1=Yes, and it works well; 2=Yes, but it doesn’t work or isn’t appropriate; 3=No, but I need it; 4=No, because it’s broken or not appropriate; 5=No, I don’t need it</p>	Hearing or communication aids are, for instance, usual hearing devices, a visual or vibrating alarm, a cochlear implant or a voice amplifier, among others.
H13	<p><b>Do you know how to keep your assistive device in good working condition?</b></p> <p>1=Yes; 2=No; 3=Not applicable</p>	This refers to the respondent either being able to repair or maintain the assistive device themselves so it works as it should, or knowing someone who can repair or maintain it for them.



## EDUCATION COMPONENT

This component includes general questions as well as questions tackling the elements of early childhood, primary, secondary and higher education, non-formal education and lifelong learning. One question in this section was taken from the UNICEF MICS3 Questionnaire for Children Under Five (<http://mics.unicef.org/tools?round=mics3>) and one from the Model Disability Survey (<http://www.who.int/disability/data/mds/en/>). **Response options in blue must not be read by the interviewer aloud.**

Item	Question and response options	Explanations
E01	<p><b>What is the highest level of education you have achieved, or are working to achieve?</b>            1=No schooling or never completed any grade; 2=Elementary education; 3=Vocational education; 4=Professional training; 5=Secondary school; 6=College; 7=University; 8=Post-graduate studies; 9=Other</p>	<p>Targets highest level of education completed (either at a formal school or at home).            For example, if the respondent attended 3 months of the first year of elementary school but did not complete the year, record “No schooling or never completed any grade”.            The categories of educational levels vary across countries and country-specific guidance for how to complete this question is needed.</p>
E02	<p><b>Where did/do you receive your education?</b>            1=Regular institutions; 2=Specialized institutions; 3=Home-schooling; 4=Other forms of education</p>	<p>A “regular institution” refers to mainstream schools, while “specialized institutions” refer to schools or facilities organized specifically for students with disability or special needs.  <b>If the respondent attended more than one type of instruction, select all that apply.</b></p>
E03	<p><b>Does [NAME] attend any organized learning or early childhood education programme, whether offered by a private or government facility, including kindergarten or community child care?</b>            1=Yes; 2=No</p>	<p>This can be a formal programme such as a government, school or office-run kindergarten or day programme, or an informal programme such as a day-care programme run by a community member.</p>
E04	<p><b>Do you participate in learning opportunities to improve your skills for everyday life or work?</b>            1=Yes; 2=No</p>	<p>This can be formal or informal education or training programmes. For example secondary school or university, trade school, learning through an apprenticeship programme, distance or online learning programmes, among others.</p>
E05	<p><b>To what extent does it fit your needs?</b>            1=Not at all; 2; 3; 4; 5=Completely</p>	<p>Respondents should reflect on how useful or helpful they found their education or training to be in relation to their needs, using a scale of 1 to 5, where 1 means not at all and 5 completely.</p>



## LIVELIHOOD COMPONENT

This component includes general questions as well as questions tackling financial services, employment, and social security benefits. Some of the questions are derived from the Alpha-Version of the WHO Web Based Model Disability Survey (<http://www.who.int/disability/data/mds/en/>). **Response options in blue must not be read aloud by the interviewer.**

Item	Question and response options	Explanations
L01	<p><b>What is your current working situation?</b>            1=Not working and looking for work; 2=Not working for wages and not looking for paid work; 3=Working for wages or salary with an employer (full- or part-time); 4=Working for wages, but currently on sick leave for more than 3 months; 5=Self-employed or own-account worker; 6=Working as unpaid family member (e.g. working in family business); 7=Retired because of the health condition; 8=Retired because of age; 9=Early retirement; 10=Other</p>	<p>Respondents should think of their current working situation.</p> <p>If their response does not match an option, select “Other”.</p>
L02	<p><b>Do you have enough money to meet your needs?</b>            1=Not at all; 2; 3; 4; 5=Completely</p>	<p>Ask this question regardless of the respondent’s state of health or whether the person is employed or not. Determine the respondent’s view of how his or her financial resources (and other exchangeable resources) and the extent to which these resources meet the needs for a healthy and comfortable life style. Focus on what the respondent can afford or cannot afford which might affect quality of life. Individual interpretation of “enough” and “meeting my needs” may vary greatly. Ensure that questions are framed to allow this variation to be accommodated. Answer should be given using a scale of 1 to 5, where 1 means not at all and 5 completely.</p>
L03	<p><b>Do you get to decide how to use your money?</b>            1=Not at all; 2; 3; 4; 5=Completely</p>	<p>Respondents should think of how much command they have over their economic resources. This includes deciding to use money to purchase items or services, or deciding to save money earned. If the respondent does not earn their own income it can be asked if they think they would get to decide if they had their own money, or if they are included in family financial decisions. Answers should be given using a scale of 1 to 5, where 1 means not at all and 5 completely.</p>
L04	<p><b>Do you know how to get financial services such as credit, insurance, grants, savings programs?</b>            1=Yes; 2=No</p>	<p>These can be any financial services from a bank, community microfinance provider or other provider of funds. The financial services should be related to the respondent’s work.</p>
L05	<p><b>Do you currently benefit from any social protection programme, such as loss of income through old age, sickness or disability?</b>            1=Yes; 2=No</p>	<p>Social protection programmes refer to public assistance that is funded either by general tax revenues or contributory schemes including welfare, poverty or needs-based compensation, accident or unemployment insurance, or pension schemes.</p>
L06	<p><b>Do you know how to get social protection against loss of income resulting from old age, sickness or disability?</b>            1=Yes; 2=No</p>	<p>Social protection programmes refer to public assistance that is funded either by general tax revenues or contributory schemes including welfare, poverty or needs-based compensation, accident or unemployment insurance, or pension schemes.</p>



## SOCIAL COMPONENT

This component includes general questions as well as questions tackling the specific elements. Some of the questions are derived from the Alpha-Version of the WHO Web Based Model Disability Survey (<http://www.who.int/disability/data/mds/en/>) and from the WHO Quality of Life-BREF ([http://www.who.int/substance\\_abuse/research\\_tools/whoqolbref/en/](http://www.who.int/substance_abuse/research_tools/whoqolbref/en/)).

**Response options in blue must not be read aloud by the interviewer.**

**For all questions of this section, answers should be given using a scale of 1 to 5, where 1 means not at all and 5 completely.**

Item	Question and response options	Explanations
S01	<p><b>Do you feel that other people respect you? For example, do you feel that others value you as a person and listen to what you have to say?</b></p> <p>1=Not at all; 2; 3; 4; 5=Completely</p>	This includes the respondent's opinion on people showing them consideration and treating them with respect.
S02	<p><b>Do you get to make decisions about the personal assistance that you need (who assists you, what type of assistance, when to get assistance)?</b></p> <p>1=Not at all; 2; 3; 4; 5=Completely</p>	Personal assistance can be anything that supports the respondent in their daily activities, such as support for self-care, mobility, maintenance of performance at school or work, home-making or home-maintenance, or child care.
S03	<p><b>Do you get to make your own decisions about your personal relationships, such as friends and family?</b></p> <p>1=Not at all; 2; 3; 4; 5=Completely</p>	Respondents should think about the attitudes of family, friends and community members, and the amount of freedom they have when initiating, maintaining or terminating personal relationships. Personal relationships include informal social relationships (friends, neighbors, peers, acquaintances), and family relationships.
S04	<p><b>Do you get to participate in artistic, cultural or religious activities?</b></p> <p>1=Not at all; 2; 3; 4; 5=Completely</p>	This includes going to art galleries, cinemas or theatres, engaging in crafts or hobbies, playing musical instruments, attending church, temple, mosque or synagogue, traditional rituals and practices, among others. The point can be made that this does not just refer to whether or not they participate, as they may not be something they wish to do. However, the respondent should reflect on whether it would be possible to participate if it is something she or he wanted.
S05	<p><b>Do you get to participate in community recreational, leisure and sports activities?</b></p> <p>1=Not at all; 2; 3; 4; 5=Completely</p>	This includes any form of informal or organized play and sports, physical fitness programmes, relaxation, amusement or diversion, engaging in games with rules or unstructured games such as playing chess or cards or children's play. The point can also be made that it does not just refer to whether or not they participate, as they may not wish to participate. However, the respondent should reflect on whether it would be possible to participate if it is something she or he wanted.
S06	<p><b>To what extent do you know your legal rights?</b></p> <p>1=Not at all; 2; 3; 4; 5=Completely</p>	This means legislation, regulations and standards including laws, customary law, religious law, international laws and conventions that govern the administration of justice.
S07	<p><b>Do you know how to access the justice system?</b></p> <p>1=Yes; 2=No</p>	Justice system refers to both formal and informal systems, courts, tribunals and other agencies for hearing and setting legal and criminal disputes, attorney representation, services of notaries, mediation, arbitration, and correctional and penal facilities, or community networks (see Glossary).



## EMPOWERMENT COMPONENT

This component includes general questions as well as questions tackling the specific elements. Some of the questions are derived from the Alpha-Version of the WHO Web Based Model Disability Survey (<http://www.who.int/disabilities/data/mds/en/>) and from the WHO Quality of Life-BREF ([http://www.who.int/substance\\_abuse/research\\_tools/whoqolbref/en/](http://www.who.int/substance_abuse/research_tools/whoqolbref/en/)).

Item	Question and response options	Explanations
M01	<p><b>Do you get to make the big decisions in your life? For example, deciding who to live with, where to live, or how to spend your money?</b></p> <p>1=Not at all; 2; 3; 4; 5=Completely</p>	Respondents should evaluate to what extent they can make their own choices about big decisions such as deciding where to live, or who to live with, or how to spend their own money. Answers should be given using a scale of 1 to 5, where 1 means not at all and 5 completely.
M02	<p><b>Do you think that the policies in your country provide people with disability equal rights as other people?</b></p> <p>1=Not at all; 2; 3; 4; 5=Completely</p>	Rights include freedom of speech, association, religion, protection against unreasonable search and seizure, the right to legal counsel such as a lawyer, the right to a trial, or protection against discrimination. Answers should be given using a scale of 1 to 5, where 1 means not at all and 5 completely.
M03	<p><b>Are you satisfied with your ability to persuade people of your views and interests?</b></p> <p>1=Not at all; 2; 3; 4; 5=Completely</p>	The ability to persuade refers to having an opinion and being able to make oneself heard. Answers should be given using a scale of 1 to 5, where 1 means not at all and 5 completely.
M04	<p><b>Do you get to influence the way your community is run?</b></p> <p>1=Not at all; 2; 3; 4; 5=Completely</p>	This refers to developing the community environment for greater accessibility and safety, or adaptation of policies and practices as needed, among others. Answers should be given using a scale of 1 to 5, where 1 means not at all and 5 completely.
M05	<p><b>Did you vote in the last election?</b></p> <p>1=Yes; 2=No</p>	This question targets whether the respondent has voted or not in the last election; no further information should be requested.
M06	<p><b>Are you a member of a self-help group?</b></p> <p>1=Yes; 2=No, but I would like to; 3=No, I don't want to</p>	A self-help group can be any informal, voluntary group of people who come together to address their common problems, or interests. For example: mothers' group, diabetes group, among others.
M07	<p><b>To what extent do you feel Disabled People's Organizations adequately represent your concerns and priorities?</b></p> <p>1=Not at all; 2; 3; 4; 5=Completely</p>	A Disabled People's Organization, or DPO, is a united group that advocates for the rights of people with disability in order to influence decision makers in governments and all sectors of society. DPOs usually exist at the regional or national levels. Answers should be given using a scale of 1 to 5, where 1 means not at all and 5 completely.



## ANNEX 8: USING DATA TO CALCULATE INDICATORS

The indicators are presented as percentages. The following steps demonstrate how to use the questions in the survey to calculate the percentages. The following indicator and question will be used as an example.

### Indicator

% of people with disability who know that physical activity and eating habits influence their health

### Question

Has your (doctor, CBR worker, or any other health professional) ever discussed with you the benefits of eating a healthy diet, engaging in regular physical exercise, or not smoking?

Answer: Yes or No

### Step 1. Collect the data using the survey question

Imagine the survey includes 287 people (the sample). This 287 includes,

134 people with disability (56 women and 78 men)

153 people without disability (81 women and 72 men)

*\* The survey also separates (disaggregates) adults and children, but for the purposes of this example, the data is disaggregated only by gender.*

From this sample, the following answers to the question were received:

With disability			Without disability		
	Yes	No		Yes	No
Men (78)	30	48	Men (72)	59	13
Women (56)	16	40	Women (81)	65	16
<b>Total</b>	<b>46</b>	<b>88</b>	<b>Total</b>	<b>124</b>	<b>29</b>

### Step 2. Calculate the percentage

» A percentage is calculated using the following formula:

$$\frac{\text{Part}}{\text{Whole}} \times 100$$



**‘Whole’ refers to the entire sample** (either all people with disability, all people without disability, or the total number of men or women in either category depending on what group you wish to look at). **‘Part’** is the number of men or women (or both) with or without disability who answered “yes” (because this indicator shows how many people do know). For example, to calculate the percentage of **women with and without disability that answered “Yes”** (the ‘part’= 16 and 65 respectively), the whole would be the complete number of women with disability (56) and all women without disability (81). The formula would therefore be used as follows:

Women with disability	Women without disability
$\frac{16}{56} \times 100 = 28.6\%$	$\frac{65}{81} \times 100 = 80.2\%$

The indicator would therefore be:

**28.6% of women with disability know that physical activity and eating habits influence their health, compared to 80.2% of women without disability.**

The same calculation can be repeated for men with disability and for men without disability. Alternatively, to compare the total number of people with disability to the total number without disability that answered “Yes”, simply add the number of men and women in each category that answered “Yes” (46 with disability and 124 without) and enter this number as the ‘part’. In this case, ‘whole’ is the complete number of men and women in each category (with or without disability) (134 and 153 respectively).

People with disability	People without disability
$\frac{46}{134} \times 100 = 34.3\%$	$\frac{124}{153} \times 100 = 81\%$

The indicator would therefore be:

**34.3% of people with disability know that physical activity and eating habits influence their health compared to 81% of people without a disability.**



## ANNEX 9: GENERATING VISUAL REPRESENTATIONS OF DATA

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After submitting completed interviews through the app, data will be organized so that indicator results can be presented as diagrams. These diagrams will show the differences between people with disability and those without disability in the community surveyed, and within those groups, the differences between boys, girls, men and women.

The following is an example of how the indicators can be presented. This example shows the base indicator for empowerment, “Percentage of people with disability who get to make informed choices and decisions compared to those without disability”, which was collected from the question “Do you get to make the big decisions in your life? For example, deciding who to live with, where to live, or how to spend your money?” Each circle is the representation of the answers that have been collected for a specific group in the community.



**Figure 9. Example of a visual representation of an indicator, disaggregated by men, women, boys and girls**

Here you can compare the differences between people with and without disability



**Green shows** the percentage of people who get to make the big decisions in their life. This corresponds to those who responded “Completely” or “Mostly” to the question during the interview.

**Orange shows** the percentage who answered “Not at all”, “A little” or “Moderately” to the question, which corresponds to the indicator result of **not** getting to make the big decisions in their life.



## ANNEX 10: CASE STUDIES

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*The following case studies are hypothetical, however they draw from real-life experiences and reflect the various impacts that CBR can have. They seek to demonstrate how the indicators can capture these impacts and how they may be used to guide CBR development and stimulate programme growth.*

### **Case study 1: Using the indicators to advocate for improved access to medications for people with disability**

A district disability resource team, composed of the District Rehabilitation Officer, a representative from a local DPO, and the Director of the District Health Services, coordinate the training of CBR workers in their town. The CBR workers then carry out home-based activities with people with disability and their families. The Rehabilitation Officer supervises these workers and organizes monthly meetings with them to discuss their experiences in the field.

For quite a while the field workers have reported an increasing number of people with disability in their areas experiencing seizures, especially children. They believed that the main reason for this was a lack of access to epilepsy medication.

To investigate this problem further, the Rehabilitation Officer decided to do a survey using the WHO CBR indicators. All base indicators would be used, as well as selected supplementary indicators on access to health care. The CBR workers collected data in households both with and without people with disability. After completing the data collection, the district disability resource team and the CBR workers met to discuss the results.

The results showed that people with disability in the town have significantly less access to medical care than people without disability (Graph 1). This strongly supported the assumption prior to data collection that people with disability in the area face barriers in accessing medication. Additionally, data from the base indicator on livelihood showed that people with disability report much greater problems in having enough money to meet their needs than those without disability (Graph 2). Follow up interviews with families who reported lack of access to medication for epilepsy reconfirmed the link between lack of money and not being able to buy this medication.

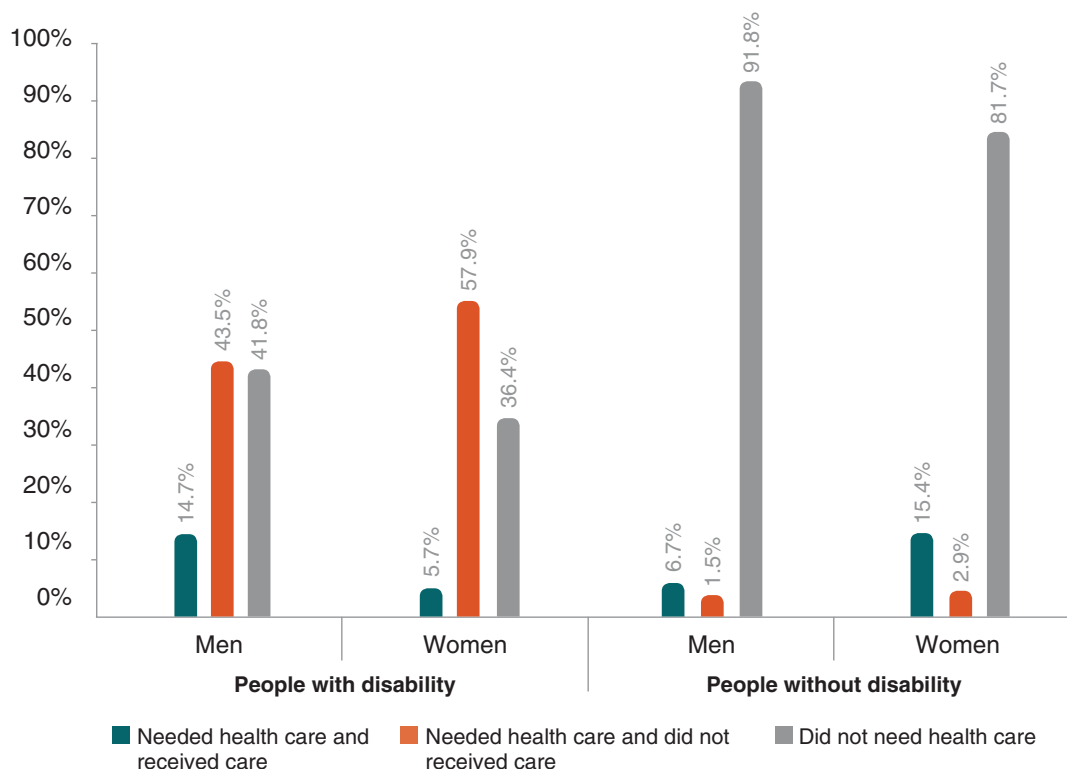
The Director of the District Health Services then compared the data collected on access to health care and finances in her town with national data on these topics, available from the WHO CBR data collection platform, and concluded that the results were similar across the country. She contacted her colleagues in other districts to call for meetings at the Ministry of Health and with pharmaceutical companies, to advocate for better access to medications for people with disability.

Meanwhile, the Rehabilitation Officer, together with the CBR workers, prepared a stakeholder meeting with people with disability, local DPOs, social workers and a representative of the local Chamber of Commerce to gather ideas about how people with disability and their family members can have better access to livelihood and social protection programmes.

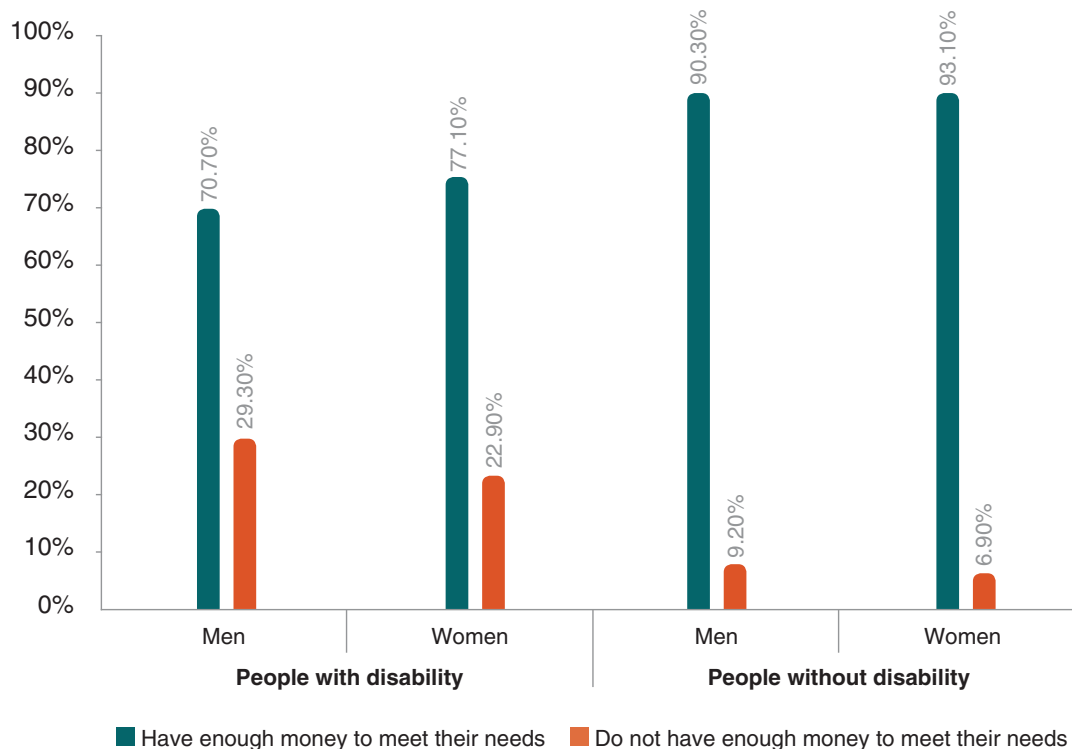
The district rehabilitation team plans to repeat the survey after 1 year to see whether their efforts at a local level led to improvements, and to then compare their results with other teams in the country.



**Graph 1. Results from the indicator on access to health care: in the last 12 months, has there been a time when you needed health care but did not get that care?**



**Graph 2. Results from the question on livelihood: do you have enough money to meet your needs?**



## **Case study 2: Using the indicators to provide baseline information to guide programme development and advocate for financial support**

The Ministry of Social Security is supporting an initiative to implement CBR in one municipality through the Ministry's local branch. Some of its staff are being allocated to this task in cooperation with a local DPO. Two social workers and two people with disability from local communities have been receiving CBR training and are acting as CBR advisors in the municipality. They are expected to coordinate the implementation of CBR and to provide feedback after 2 years on how best to initialize CBR in other municipalities.

The CBR team was aware that they needed comprehensive and reliable baseline data before deciding which area of the CBR matrix they would target. They trained local students to interview people with and without disability in their communities, using all questions from the WHO CBR indicator set.

After completing the data collection, the CBR team arranged to present and discuss their results at a meeting of the municipal assembly. The members of the assembly discussed these results and decided that gaps in access to rehabilitation services and livelihood opportunities for people with disability should be prioritized.

The municipal assembly advised further CBR implementation in coordination with primary health services, the local labor office and mainstream nongovernmental organizations (NGOs) working in income generation. A subsequent meeting with these stakeholders included a more in-depth analysis of the baseline data and resulted in a 2 year action plan that was submitted for approval to the Ministry of Social Security.

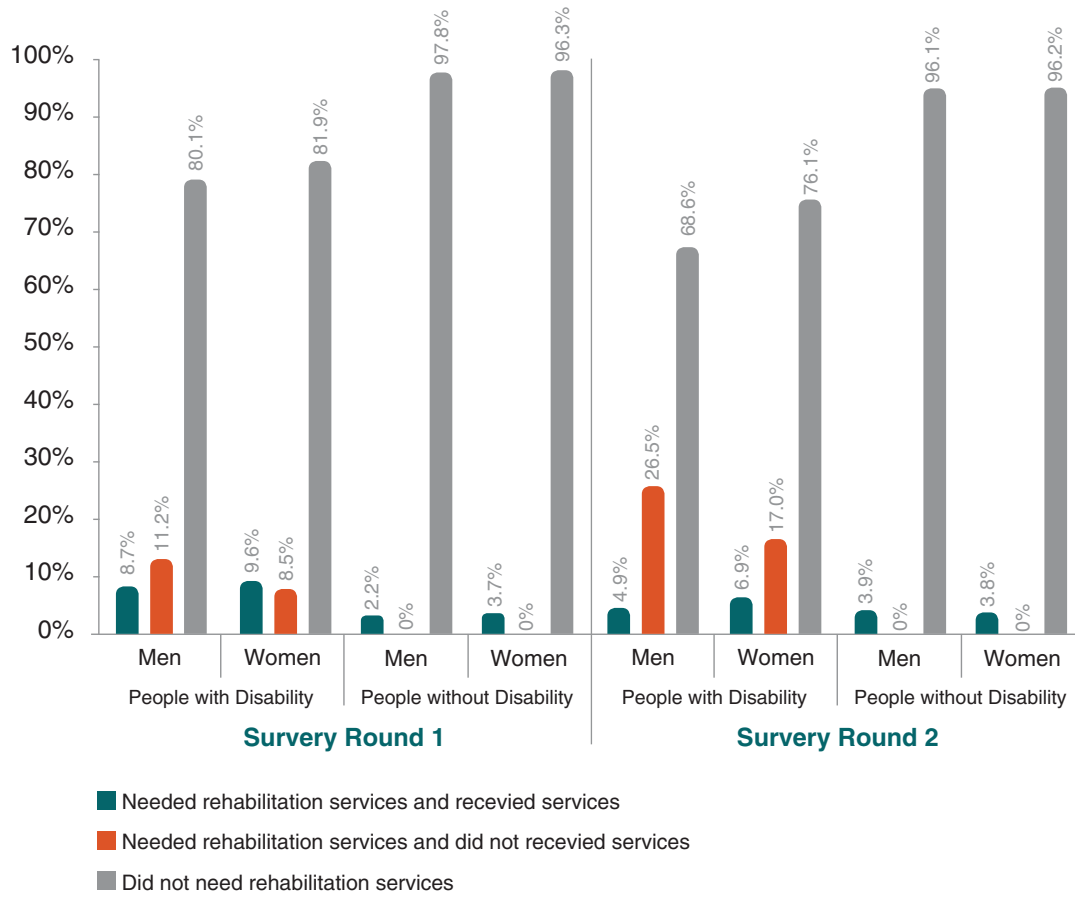
The ministry stated that they do not have sufficient funds to implement the action plan beyond the first year. Therefore, the CBR team decided to approach the Ministry of Health for further financial support for the rehabilitation aspect of their work. To this ministry they presented a summary of the baseline data, the municipal assembly's recommendations, and the action plan. Additionally, they submitted a joint proposal together with the NGO working on income generation to a grant foundation to apply for funds for the support of disability-inclusive vocational training courses.

The CBR initiative won the tender for the vocational training courses and began implementation, but the Ministry of Health rejected their proposal. The team decided to repeat the data collection after 1 year, and also to include some of the indicators in their regular monitoring system, so they would be able to prove the effectiveness of their livelihood programme. The new data set showed a significant drop in access to rehabilitation services for people with disability compared with the previous year (Graph 1).

These results received media coverage which led to increased political pressure on the Ministry of Health. As a result, the ministry entered talks about future funding possibilities.



**Graph 1. Results from the question on access to rehabilitation services: in the last 12 months, has there been a time when you needed rehabilitation services but did not get those services?**



### **Case study 3: Using the indicators to facilitate the identification of barriers to education and expand CBR programmes**

A CBR programme in a rural region mainly conducts home visits to families with children with disability. During these visits they address access to rehabilitation and to primary health care, as well as supporting parents and mainstream schools in enrolling children with disability.

Each year CBR personnel conduct an annual meeting to review their objectives and activities for the coming year. In this meeting, field workers explained that they have been experiencing a problem for quite some time: despite their efforts, many children with disability are still not enrolled in school. They were struggling to find the right strategy to address this issue, but they did not have a systematic understanding of the reasons behind the problem.

Based on this, the CBR team decided to conduct a survey using the WHO CBR indicators involving children with and without disability, so they could capture inequalities. They used all the base indicators to get a more comprehensive overview of the situation of the children living in their area. Additionally, they included the supplementary indicators for education to help gather in-depth information about this component.

The results of the survey showed that many children with disability in the region had not completed primary education, while nearly all children without disability had completed primary or secondary education (Graph 1). Additionally, analysis of base indicators showed that children with disability rated their health as worse than children without disability (Graph 2).

One year later the survey was repeated to check up on the changes in the community. The results showed an improvement in school enrolment but no significant improvement in health status (Graphs 1 and 2).

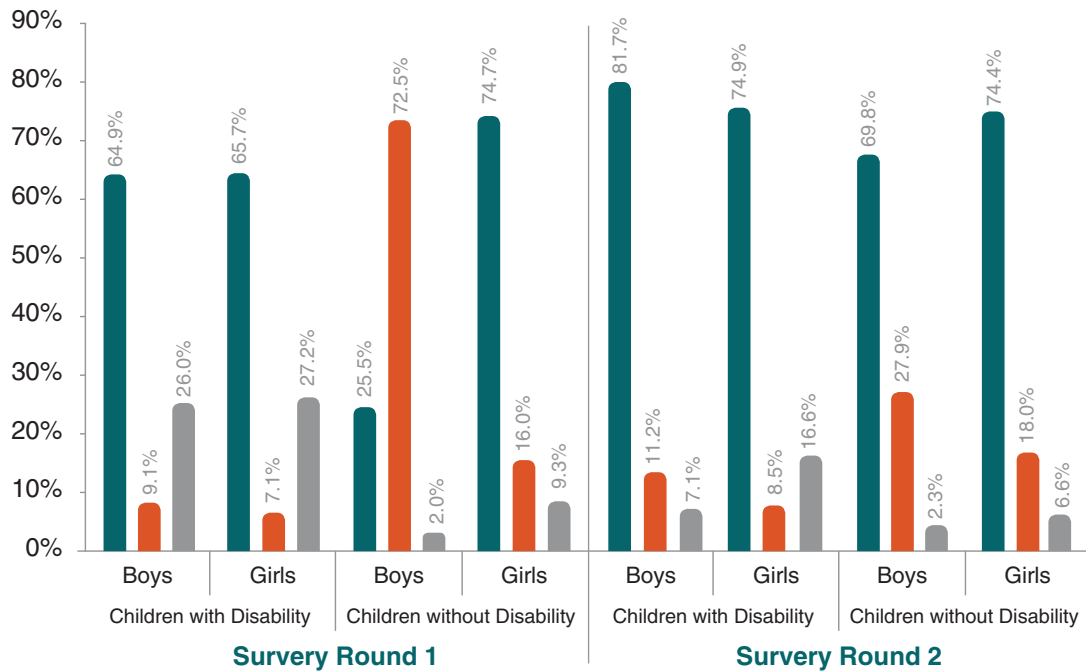
As a consequence of this result, the CBR coordinator decided to organize visits to primary health facilities and to conduct interviews with some parents to better understand the reasons for the worse health status of children with disability. Additionally, it was decided that in future, data collection activities an additional supplementary indicator from the health component about visits to health-care centers would be included to monitor possible reasons for reported health differences.

Subsequently the CBR manager organized a stakeholder meeting with school headmasters, local school authorities and representatives of parent-teacher associations to discuss these results and identify the barriers to school inclusion. They found the main hindering factors to be physical access to classrooms and lack of awareness of teachers regarding disability issues.

The CBR coordinator, along with coordinators of other CBR initiatives in the country and local school authorities, used this information to lobby the Ministry of Education to provide ramps and organized disability awareness training sessions with local teachers.

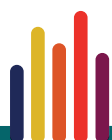


**Graph 1. Results from the indicator on education, using the question: what is the highest level of education you have completed or are completing? The percentage of children with disability completing or having completed schooling in comparison to children without disability is presented for the first and second round of the survey.**

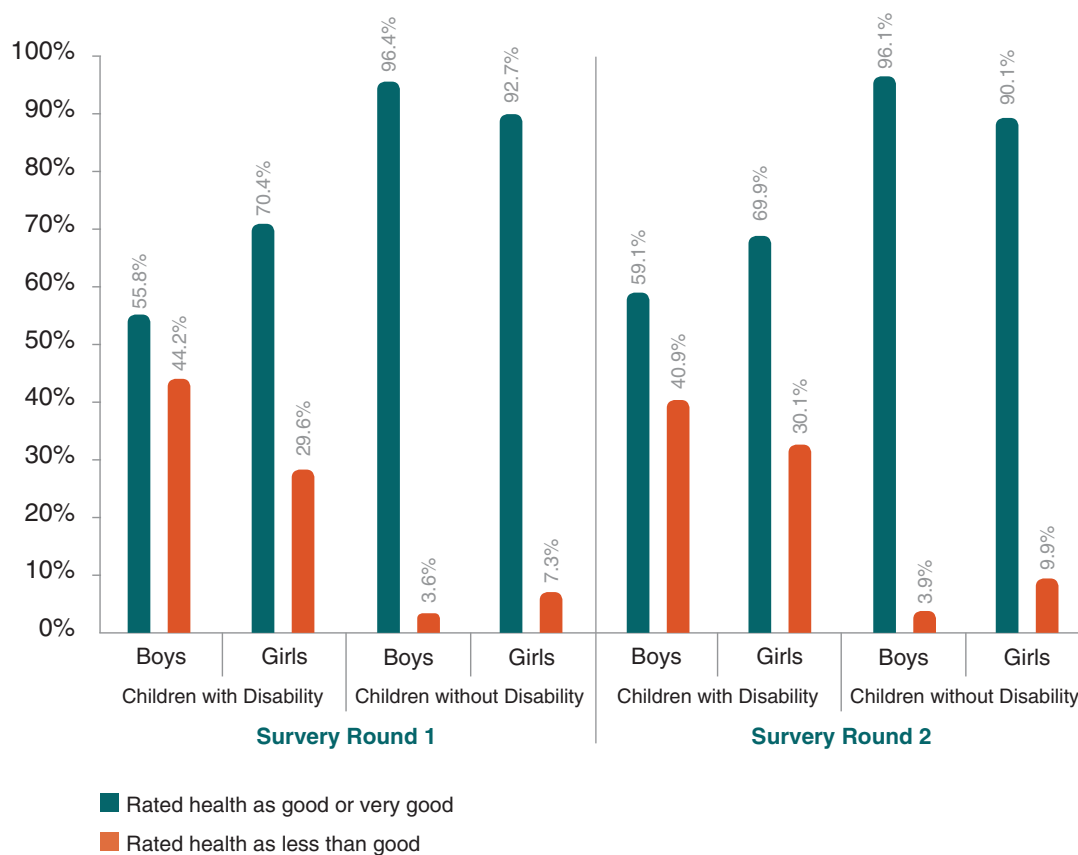


Highest level of education completed:

- No schooling completed
- Completed or completing primary education
- Completed or completing secondary education



**Graph 2. Results from the question on health: how would you rate your health today? No large changes in the reported health status were seen between the first and second surveys.**



# ANNEX 11: EXAMPLE CONSENT FORM

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**Dear participant,**

**Selection** You have been selected to be part of this survey and this is why we would like to interview you. This survey is conducted by the [enter name of organization, institution or government body] and will be carried out by interviewers from [name of place interviewers have been selected from]. This survey is currently taking place in several areas around the world.

**Confidentiality** The information you provide is totally confidential and will not be disclosed to anyone. It will only be used for the purposes of showing the difference between people with disability and people without disability in this area. Only a code will be used to connect your name and your answers without identifying you.

**Voluntary participation** Your participation is voluntary and you can withdraw from the survey after having agreed to participate. You are free to refuse to answer any question that is asked in the questionnaire. If you have any questions about this survey you may ask me or contact [name of person, organization or government body to contact] or [Principal Investigator at site].

**Consent to participate** Signing this consent indicates that you understand what will be expected of you and are willing to participate in this survey.

<b>Read by participant</b>		<b>Interviewer</b>	
<b>Agreed</b>		<b>Refused</b>	

**Signatures** I hereby provide INFORMED CONSENT to take part in the survey.

<b>Name:</b>	<b>Sign:</b>
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<b>Parent/Guardian:</b>	<b>Sign:</b>
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# ANNEX 12:

## GLOSSARY

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### **Assistive device**

Any device designed, made or adapted to help a person perform a particular task. Products may be specially produced or generally available for people with a disability.<sup>1</sup>

### **Base CBR Indicators**

A set of 13 indicators that WHO recommends are always included in CBR monitoring.<sup>2</sup>

### **Community-based rehabilitation (CBR)**

A strategy within general community development for rehabilitation, equalization of opportunities, poverty reduction, and social inclusion of people with disability. CBR is implemented through the combined efforts of people with disability themselves, their families, organizations, and communities, and the relevant governmental and nongovernmental health, education, vocational, social, and other services.<sup>1</sup>

### **CBR matrix**

A visual representation of CBR that illustrates the different sectors that can make up a CBR strategy.<sup>6</sup>

### **Customized option**

The app can be customized to include any additional questions targeting supplementary CBR indicators. An interview including all questions for base and supplementary CBR indicators would take approximately 20 minutes to complete.<sup>2</sup>

### **Default option**

The Default option of the app includes all questions targeting base CBR indicators. An interview with the default option will take approximately 5 minutes to complete.<sup>2</sup>

### **Disabled People's Organizations (DPOs)**

Organizations or assemblies established to promote the human rights of disabled people, where most of the members as well as the governing body are people with disability.<sup>1</sup> They advocate for the rights of people with disability in order to influence decision makers in governments and all sectors of society. DPOs usually exist at the regional or national levels.<sup>2</sup>

### **Disability**

Disability is defined in the International Classification of Functioning, Disability and Health as an umbrella term for impairments, activity limitations, and participation restrictions, denoting the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).<sup>1</sup>

### **Educational certificate**

An education certificate refers to that received from a recognized institution, such as schools, colleges or universities.<sup>10</sup>



## **Financial services**

Any financial service from a bank, community microfinance provider or other recognized provider of funds. The financial services should be related to the respondent's work.<sup>2</sup>

## **Health check-ups**

In the context of this manual, a health check-up refers to a medical visit meant to prevent sickness or to identify a health condition in an early stage. This does NOT refer to going to a doctor because of illness or for a disability-related problem.

## **International Disability and Development Consortium (IDDC)**

A global consortium of 28 disability and development nongovernmental organizations (NGOs), mainstream development NGOs and DPOs supporting disability and development work in more than 100 countries around the world.<sup>7</sup>

## **Indicator(s)**

Quantitative or qualitative factor(s) or variable(s) that provide(s) simple and reliable means to measure achievement, to reflect the changes connected to an intervention, or to help assess the performance of a development actor.<sup>9</sup>

## **Justice system**

In the context of this manual, the justice system refers to both formal and informal systems. Formal justice systems include courts, tribunals and other agencies for hearing and settling legal and criminal disputes, attorney representation, services of notaries, mediation, arbitration and correctional or penal facilities. Informal justice systems include those accessed in community networks, such as local leaders, heads of families, school administration, farming cooperatives or banks.<sup>12</sup>

## **Non-formal education**

Non-formal education refers to education that occurs outside the formal school system and is often used interchangeably with terms such as community education, adult education, lifelong education and second-chance education. It refers to a wide range of educational initiatives in the community, ranging from home-based learning to government schemes and community initiatives. It includes accredited courses run by well-established institutions as well as locally based operations with little funding.<sup>10</sup>

## **Legal rights**

Refers to legislation, regulations and standards including laws, customary law, religious law, international laws and conventions that govern the administration of justice.

## **Lifelong learning**

Refers to all purposeful learning activities undertaken on an ongoing basis throughout a person's life, with the aim of improving knowledge, skills and competencies.<sup>3</sup>

## **Livelihood**

The means by which an individual secures the necessities of life. It may involve work at home or in the community, work alone or in a group, or for an organization, a government body, or a business. It may be work that is remunerated in kind, in cash, or by a daily wage or a salary.<sup>1</sup>



### **Mock-interview**

A practice interview prior to performing it with the intended interviewee. The intention is to emulate the real interview process as closely as possible.

### **Monitoring**

A continuous descriptive process that uses the systematic collection of data to give information on where a policy, programme or project is at any given time, and over time relative to respective targets and outcomes.<sup>8</sup>

### **Own-account worker**

A person who operates his or her own economic enterprise, or engages independently in a profession or trade, and hires no employees.<sup>11</sup>

### **Personal assistance**

Anything that supports the respondent in their daily activities, such as support for self-care, mobility, maintenance of performance at school or work, home-making or home-maintenance, or child care.

### **(Health) Promotion**

The process of enabling people to increase control over, and improve, their health.<sup>1</sup>

### **Prevention**

**Primary prevention** – actions to avoid or remove the cause of a health problem in an individual or a population before it arises. It includes health promotion and specific protection (for example, HIV education).<sup>1</sup>

**Secondary prevention** – actions to detect a health problem at an early stage in an individual or a population, facilitating cure, or reducing or preventing spread, or reducing or preventing its long-term effects (for example, supporting women with intellectual disability to access breast cancer screening).<sup>1</sup>

**Tertiary prevention** – actions to reduce the impact of an already established disease by restoring function and reducing disease-related complications (for example, rehabilitation for children with musculoskeletal impairment).<sup>1</sup>

### **Professional training**

Training that leads to a professional occupation, such as a doctor or lawyer.

### **Rehabilitation**

A set of measures that assists individuals who experience, or are likely to experience, disability, in order to achieve and maintain optimal functioning in interaction with their environments.<sup>1</sup>

### **Self-help groups**

Any informal, voluntary group of people that comes together to address common problems or interests.<sup>2</sup>

### **Social protection**

Public assistance that is funded either by general tax revenues or contributory schemes including welfare, poverty or needs-based compensation, accident or unemployment insurance, or pension schemes.<sup>2</sup>



### **Social protection programmes**

Programmes to reduce deprivation arising from conditions such as poverty, unemployment, old age, and disability.<sup>1</sup>

### **Supplementary CBR indicators**

A set of 27 additional indicators from which users may select the ones that match a specific community's CBR strategies and goals.

### **Regular (educational) institution**

In the context of this manual, regular (educational) institutions refer to mainstream schools.<sup>2</sup>

### **Specialized (educational) institution**

In the context of this manual, specialized (educational) institutions refer to schools or facilities organized specifically for students with disability or special needs.<sup>2</sup>

### **WHO Global Disability Action Plan 2014–2021**

A report endorsed by the 67<sup>th</sup> World Health Assembly that seeks to remove barriers and improve access to health services and programmes; strengthen and extend rehabilitation, habilitation, assistive technology, assistance and support services, and CBR; and strengthen collection of relevant and internationally comparable data on disability and support research on disability and related services.<sup>5</sup>

### **WHO Model Disability Survey (MDS)**

A general population survey that provides detailed and nuanced information on the lives of people with disability. It allows direct comparison between groups with differing levels and profiles of disability, including comparison to people without disability. The evidence resulting from the MDS will help policy-makers identify which interventions are required to maximize the inclusion and functioning of people with disability.<sup>4</sup>



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