

Capturing the difference we make

Community-based Rehabilitation Indicators Manual



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ABBREVIATIONS

CBR	Community-based rehabilitation
CRPD	Convention on the rights of persons with disabilities
DPO	Disabled people's organization
IDDC	International Disability and Development Consortium
MDS	Model disability survey
NGO	Nongovernmental organization
WHO	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 disabilities 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 disabilities 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 living with a disability and their families and those without disabilities 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 persons with disability to persons without disability aligns with the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which states that persons 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

What is contained in this manual?

This manual contains indicators capable of capturing the difference CBR makes in the lives of people with disabilities 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 differences made by CBR in the lives of people with disabilities and their families, making it possible to 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. This app can consolidate the results of data collection and automatically generate graphs.

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 disabilities in the areas where it is implemented. Annex 1 shows the context of the indicators in regards to what they capture, and Annex 6, Using Data to Inform the Indicators, and Annex 8, Case Studies, provide information on who 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

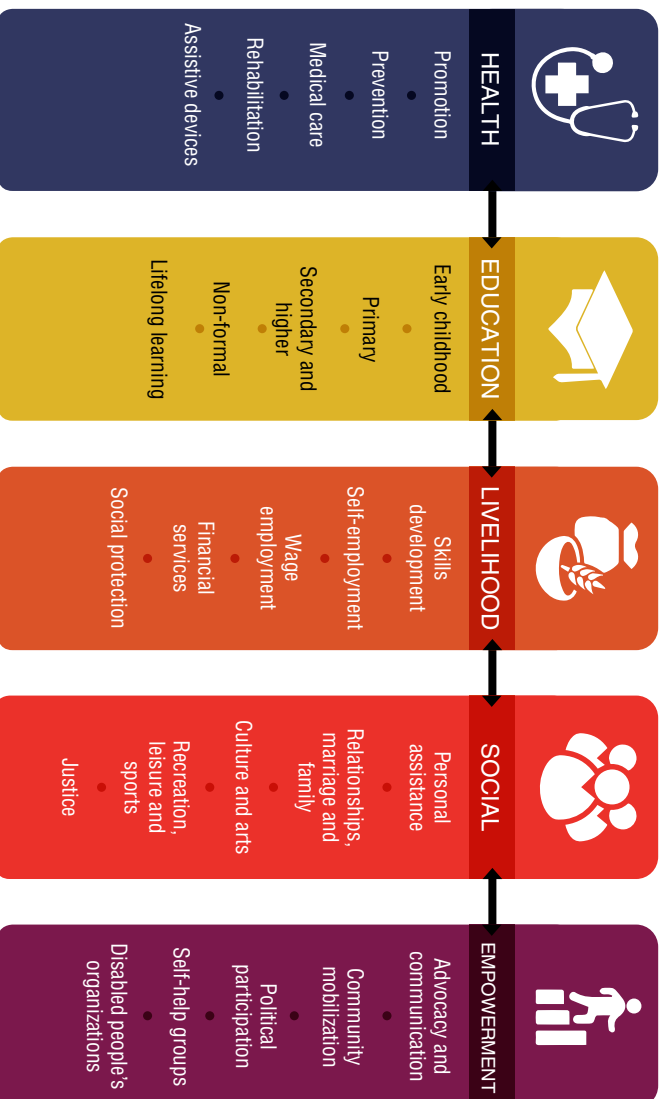
The indicators have two goals:

- » **Capturing the difference that CBR makes** in the lives of people with disabilities in the communities where it is implemented;
- » **Capturing differences** between adults, youth and children with disabilities, and those without disabilities 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



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 disabilities, 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.

SOURCING 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, the census or survey needs to target persons with disability – living conditions surveys or disability surveys are examples of sources with a clear definition of persons with disability. National or regional surveys targeting broader topics, such as labor force or education surveys, are examples where the group of persons with disability are not always clearly defined. Data from such sources can only be used if questions identifying persons 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 survey of questions** (explained in the following pages and comprehensively detailed in Annex 5), 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 5.

- » An **Android app for mobile phones** has been developed. This includes the questions to make data collection easier and more efficient. Visual representations of the collected data can be automatically generated using the app (see Annex 4).
- » If the survey is conducted using questions in this manual, it needs to be conducted in the **community where CBR is being implemented** and include persons with disability and persons without disability, independently of whether or not they participate in CBR.
- » The sample should include **all men, women, boys and girls with disabilities** 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 persons with disability.
- » A comparison group that includes **a similar number of men, women, boys and girls without disabilities** 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.

SHOWING THE DIFFERENCE

- » Data will be presented as percentages **comparing men, women, boys and girls with disabilities and those without disabilities** in the same community where CBR is implemented. Data is therefore **broken down by gender and age**. Annex 6 describes how to calculate percentages, Annex 7 shows how to generate visual representations of the information, and Annex 8 demonstrates how information can be used to instigate change in different scenarios.



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

	HEALTH	EDUCATION	LIVELIHOOD	SOCIAL	EMPOWERMENT
BASE INDICATORS	<p>% of people with disabilities who:</p> <ul style="list-style-type: none"> - rate their health as good or very good - rate their experience of being treated with respect and dignity by health service providers as good or very good 	<p>% of children with disabilities attending or completing primary education</p> <p>% of youth with disabilities attending or completing secondary education</p> <p>% of people with disabilities:</p>	<p>% of people with disabilities who:</p> <ul style="list-style-type: none"> - are self-employed or own-account workers - are working for wages or salary with an employer - have enough money to meet their needs 	<p>% of people with disabilities who feel valued as individuals by members of their community</p>	<p>% of people with disabilities who get to make informed choices and decisions</p>
SUPPLEMENTARY INDICATORS	<p>% of people with disabilities who:</p> <ul style="list-style-type: none"> - know that physical activity and eating habits influence their health - receive recommended health check-ups - have access to medical care - needed medical care in the last 12 months but did not get it - have the experience of being involved in making decisions for their treatment - have access to rehabilitation services - needed rehabilitation services in the last 12 months but did not get them - have access to assistive products appropriate to their needs - are using assistive devices and know how to maintain them 	<ul style="list-style-type: none"> - attending or completing higher education - who have educational or vocational options after obtaining their educational certificate or degree - who have professional training - who acquire education in mainstream education facilities <p>% of children with disabilities aged 36–59 months who are participating in early childhood education activities</p> <p>% of people with disabilities who use life-long learning opportunities to improve their life skills</p>	<p>% of people with disabilities who:</p> <ul style="list-style-type: none"> - get to make decisions about how to use their money - know how to access financial services - know how to access social protection measures - are covered by social protection programmes 	<p>% of people with disabilities who:</p> <ul style="list-style-type: none"> - make their own decisions about the personal assistance they need - make their own decisions about their personal relationships - participate in artistic, cultural or religious activities - participate in mainstream recreational, leisure and sports activities - know their legal rights - know how to access mechanisms of justice 	<p>% of people with disabilities who:</p> <ul style="list-style-type: none"> - know and exercise their rights - have the communication skills to express their wishes and objections effectively - have a role in shaping their communities to achieve equal opportunities for all - engage in local or national politics and in civil society organizations - actively engage in and benefit from self-help groups - feel that they are adequately represented by DPOs

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

CBR INDICATORS AND CORRESPONDING SURVEY QUESTIONS

In the following pages the CBR indicators for each component (health, education, livelihood, social and empowerment) are presented one by one on the left and the corresponding questions that can be used to inform them are presented on the right. The indicators and suggested questions for the components are broken down by the five elements of each. **Base CBR indicators and their corresponding questions are presented in bold text.**

INDICATORS FOR HEALTH

Health in general

% of people with disabilities who rate their health as good or very good compared to people without disabilities

% of people with disabilities who rate their experience of being treated with respect and dignity by health service providers as good or very good compared to people without disabilities

Promotion

% of people with disabilities and their families who know that physical activity and eating habits influence their health compared to people without disabilities

Prevention

% of people with disabilities who receive suggested health check-ups compared to people without disabilities

Medical care

% of people with disabilities who needed medical care in the last 12 months and did not get the care they needed compared to people without disabilities

% of people with disabilities who have access to medical care compared to people without disabilities

% of people with disabilities who have the experience of being involved in making decisions for their treatment compared to people without disabilities

Rehabilitation

% of people with disabilities who needed rehabilitation services in the last 12 months and did not get the services they needed

% of people with disabilities who have access to rehabilitation services

Assistive devices

% of people with disabilities who have access to assistive products appropriate to their needs

% of people with disabilities using assistive devices who know how to maintain them



SUGGESTED QUESTIONS

Health in general

In general, how would you rate your health today?

1=Very good; 2=Good; 3=Neither poor nor good; 4=Poor; 5=Very poor

On your last visit to a health-care provider, to what extent were you satisfied with the level of respect with which you were treated?

1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely

Promotion

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

When was the last time you had a regular health check-up?

1=In the last year; 2=1–2 years ago; 3=Between 2–5 years ago; 4=Longer than 5 years ago; 5=Never

Medical care

In the last 12 months, has there been a time when you needed health care but did not get that care?

1=Yes; 2=No; 3=No need for health care in the past 12 months

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 denied health-care; 12=Thought you were not sick enough; 13=Other

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

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; 2=No; 3=No need for rehabilitation services in the past 12 months

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

Assistive devices

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?

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

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

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

Do you know how to keep your assistive device in good working condition?

1=Yes; 2=No; Not applicable

INDICATORS FOR EDUCATION

Education in general

% of children with disabilities who are attending or have completed primary education compared to children without disabilities

% of youth with disabilities who are attending or have completed secondary education compared to youth without disabilities

% of people with disabilities who are attending or have completed higher education compared to people without disabilities

% of people with disabilities who have educational or vocational options after obtaining their educational certificate or degree compared to people without disabilities

% of people with disabilities who have professional training compared to people without disabilities

% of people with disabilities who acquire education in mainstream education facilities compared to people without disabilities

Early childhood education

% of children with disabilities aged 36–59 months who are participating in early childhood education activities compared to children without disabilities aged 36–59 months

Primary education

As under Education in general: % of children with disabilities who have completed primary education compared to children without disabilities

Secondary education and higher

As under Education in general:

% of youth with disabilities who are attending or have completed secondary education compared to youth without disabilities

% of people with disabilities who are attending or have completed higher education compared to people without disabilities

% of people with disabilities who have professional training compared to people without disabilities

Non-formal education

For children: % of those who select option 3 or 4 in response to the question under Education in general, *Where did/do you receive your education?* compared to children without disabilities 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 disabilities who answered “yes” to the same question.

Lifelong learning

% of people with disabilities who use life-long learning opportunities to improve their life skills compared to people without disabilities



SUGGESTED QUESTIONS

Education in general

What is the highest level of education you have achieved, or are working to achieve?

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

Where did/do you receive your education?

1=Regular institutions; 2=Specialized institutions; 3=Home-schooling; 4=Other forms of education

Early childhood education

Does [NAME] attend any organized learning or early childhood education programme, whether offered by a private or government (public) facility, including kindergarten or community child care?
1=Yes; 2=No

Primary education

As under Education in general: What is the highest level of education you have achieved, or are working to achieve?

Secondary education and higher

As under Education in general: What is the highest level of education you have achieved, or are working to achieve?

Non-formal education

For children

As under Education in general: Where did/do you receive your education?

For adults

As under Lifelong learning: Do you participate in learning opportunities to improve your skills for everyday life or work?

Lifelong learning

Do you participate in learning opportunities to improve your skills for everyday life or work?

1=Yes; 2=No

To what extent does it fit your needs?

1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely



INDICATORS FOR LIVELIHOOD

Livelihood in general

% of people with disabilities who are self-employed or own-account workers compared to people without disabilities

% of people with disabilities who are working for wages or salary with an employer compared to people without disabilities

% of people with disabilities who have enough money to meet their needs compared to people without disabilities

% of people with disabilities who get to make decisions about how to use his/her money compared to people without disabilities

Skills development

As previously under Education in general: % of people with disabilities who have educational or vocational options after obtaining their educational certificate or degree compared to people without disabilities

Self-employment

As above under Livelihood in general: % of people with disabilities who are self-employed or own-account workers compared to people without disabilities

Wage employment

As above under Livelihood in general: % of people with disabilities who are working for wages or salary with an employer compared to people without disabilities

Financial services

% of people with disabilities who know how to access financial services compared to people without disabilities

Social protection

% of people with disabilities who know how to access social protection measures compared to people without disabilities

% of people with disabilities who are covered by social protection programmes compared to people without disabilities



SUGGESTED QUESTIONS

Livelihood in general

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

Do you have enough money to meet your needs?

1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely

Do you get to decide how to use your money?

1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely

Skills development

As in Livelihood in general: What is your current working situation?

Self-employment

As in Livelihood in general: What is your current working situation?

Wage employment

As in Livelihood in general: What is your current working situation?

Financial services

Do you know how to get financial services such as credit, insurance, grants, savings programmes?

1=Yes; 2=No

Social protection

Do you know how to get social protection against loss of income through old age, sickness or disability?

1=Yes; 2=No

Do you currently benefit from any social protection programme, such as loss of income through old age, sickness or disability?

1=Yes; 2=No



INDICATORS FOR SOCIAL

Social in general

% of people with disabilities who feel valued as individuals by members of their community compared to people without disabilities

Personal assistance

% of people with disabilities who get to make their own decisions about the personal assistance they need

Relationship, marriage and family

% of people with disabilities who make their own decisions about their personal relationships compared to people without disabilities

Culture and arts

% of people with disabilities who get to participate in artistic, cultural or religious activities compared to people without disabilities

Recreation, leisure and sports

% of people with disabilities who participate in mainstream recreational, leisure and sports activities compared to people without disabilities

Justice

% of people with disabilities who know their legal rights compared to people without disabilities

% of people with disabilities who know how to access mechanisms of justice compared to people without disabilities



SUGGESTED QUESTIONS

Social in general

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

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

Relationship, marriage and family

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

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

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

To what extent do you know your legal rights?
1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely

Do you know how to access the justice system?
1=Yes; 2=No



INDICATORS FOR EMPOWERMENT

Empowerment in general

% of people with disabilities who get to make informed choices and decisions compared to people without disabilities

% of people with disabilities who know and exercise their rights compared to people without disabilities

Advocacy and communication

% of people with disabilities who have the communication skills to express their wishes and objections effectively compared to people without disabilities

Community mobilization

% of people with disabilities who have a role in shaping their communities to achieve equal opportunities for all compared to people without disabilities

Political participation

% of people with disabilities who engage in local or national politics and in civil society organizations compared to people without disabilities

Self-help groups

% of people with disabilities who actively engage in and benefit from self-help groups compared to people without disabilities

Disabled People's Organizations

% of people with disabilities who feel that they are adequately represented by Disabled People's Organizations



SUGGESTED QUESTIONS

Empowerment in general

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

Do you think that the policies in your country provide people with disabilities equal rights as other people?

1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely

Advocacy and communication

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

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

Did you vote in the last election?

1=Yes; 2=No

Self-help groups

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

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 CONTEXT¹

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 results were selected as CBR Indicators 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.

Levels of monitoring

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

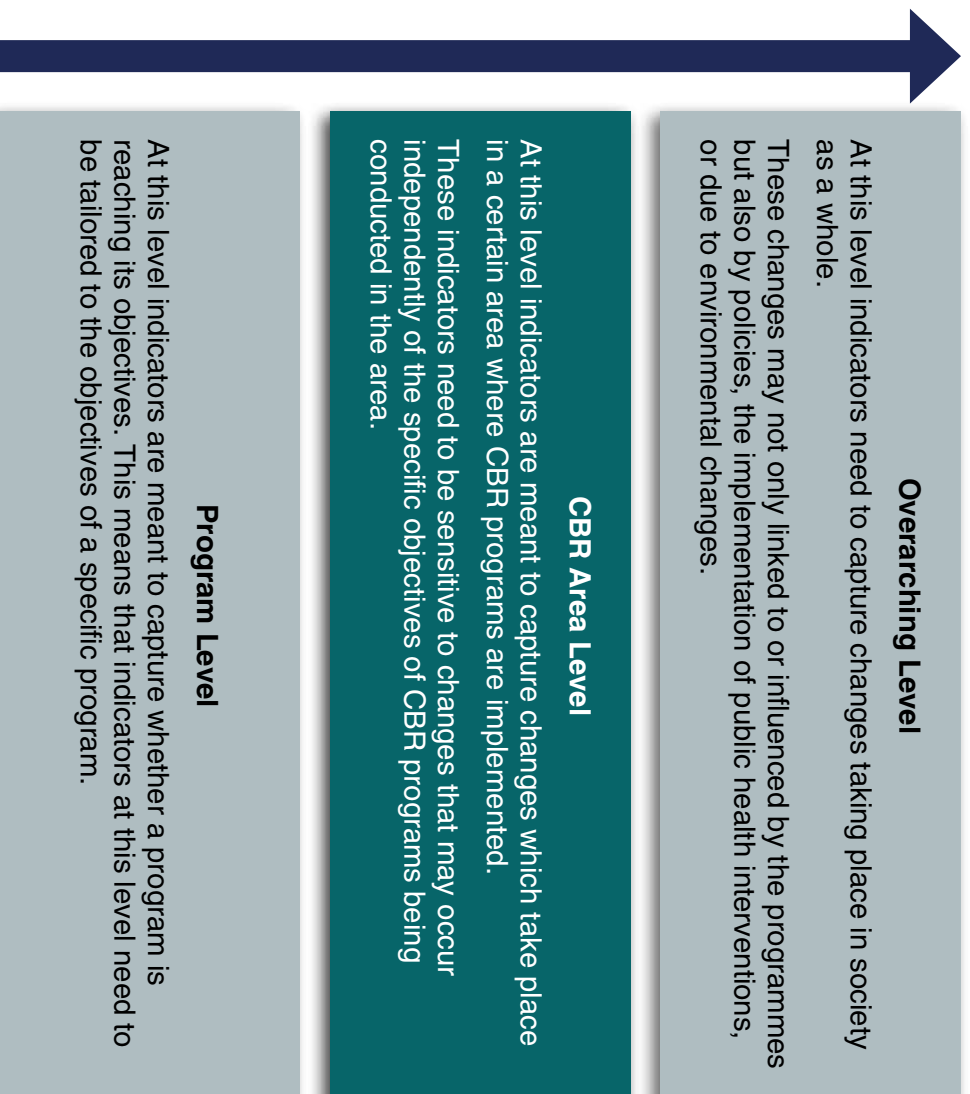
¹ This section is based on:

- 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.



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 (dark green box).

The indicators are designed to capture the difference CBR makes at the CBR area level, rather than for specific CBR programs. However, the indicators can still be used in communities where there is only one program being implemented (as has been demonstrated in Case Study 3 of Annex 8).

ANNEX 2: DEVELOPMENT OF THE CBR INDICATORS AND QUESTIONS TO INFORM THEM

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/disabilities/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/disabilities/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

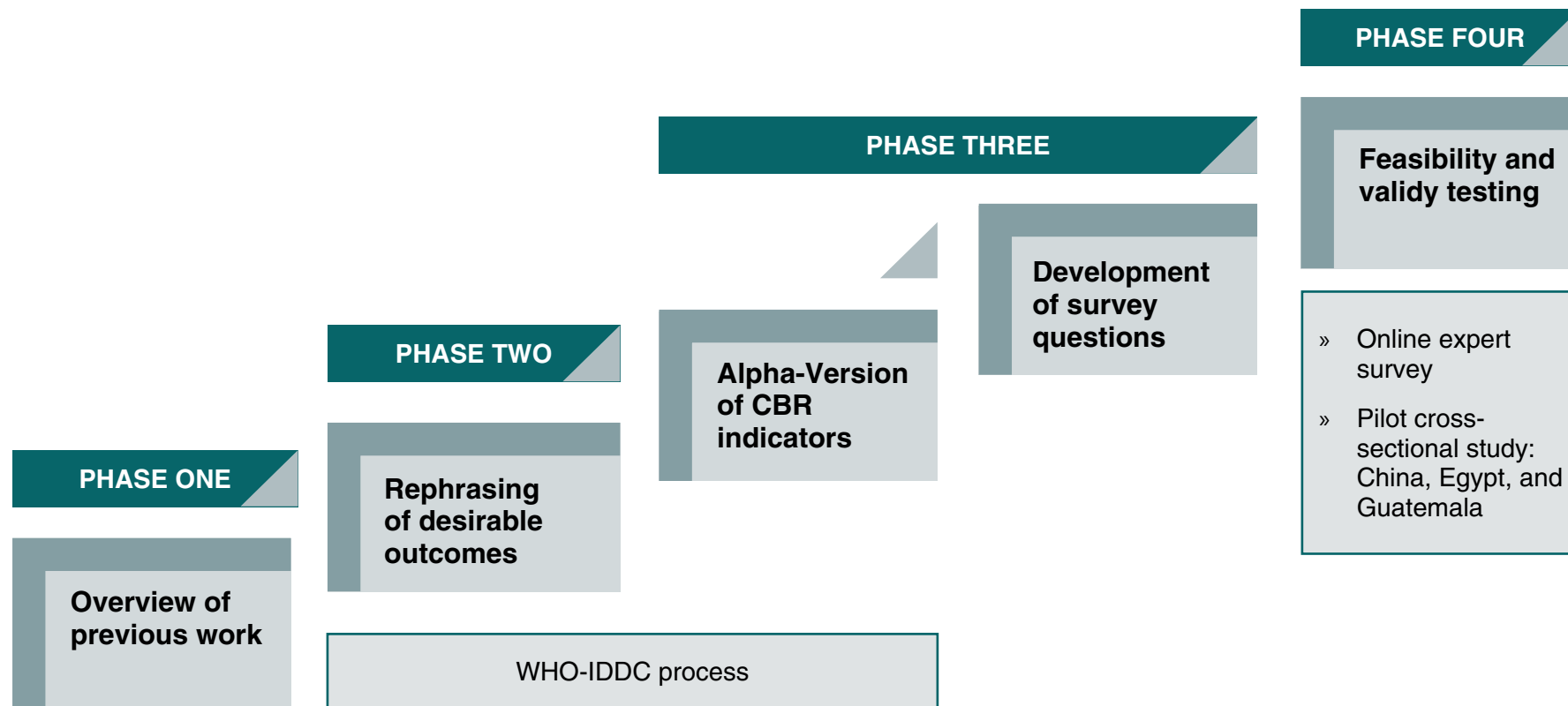
The feasibility and validity of the proposed indicators and questions were tested via two studies:

- 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 disabilities 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: 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 disabilities 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 disabilities 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 disabilities 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 disabilities 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 disabilities 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; 2=No; 3=No need for health care in the past 12 months

HEALTH			
Element	Rephrased desirable outcome	Indicator	Question
Medical care		% of people with disabilities 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 disabilities 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 disabilities 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; 2=No; 3= No need for rehabilitation services in the past 12 months
Rehabilitation		% of people with disabilities 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 disabilities 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 disabilities 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 disabilities 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 disabilities experience post-school options on an equal basis with their peers</p>	<p>% of children with disabilities who are attending or have completed primary education compared to children without disabilities</p> <p>% of youth with disabilities who are attending or have completed secondary education compared to youth without disabilities</p> <p>% of people with disabilities that are attending or have completed higher education compared to people without disabilities</p> <p>% of people with disabilities who have educational or vocational options after obtaining their educational certificate or degree compared to people without disabilities</p> <p>% of people with disabilities who have professional training compared to people without disabilities</p>	<p>What is the highest level of education you have achieved, or are working to achieve?</p> <p>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>
General education		<p>% of people with disabilities who acquire education in mainstream education facilities compared to people without disabilities</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 disabilities actively participate in early childhood developmental activities and play, either in a formal or informal environment</p>	<p>% of children with disabilities age 36–59 months who are participating in early childhood education activities compared to children without disabilities 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 disabilities participate in a variety of non-formal learning opportunities based on their needs and desires.	<p>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 disabilities who selected the same response options.</p> <p>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 disabilities who answered “yes” to the same question.</p>	<p>Where did/do you receive your education? 1=Regular institutions; 2=Specialized institutions; 3=Home-schooling; 4=Other forms of education</p> <p>Do you participate in learning opportunities to improve your skills for everyday life or work? 1=Yes; 2=No</p>
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 disabilities who use life-long learning opportunities to improve their life skills compared to people without disabilities	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	<p>Men and women with disabilities have paid and decent work in the formal and informal sector on an equal basis with others</p> <p>Women and men with disability earn income through their own chosen economic activities</p> <p>Youth and adults with disabilities acquire marketable skills on an equal basis with others through a range of inclusive training opportunities</p>	<p>% of people with disabilities who are self-employed or own-account workers compared to people without disabilities</p> <p>% of people with disabilities who are working for wages or salary with an employer compared to people without disabilities</p>	<p>What is your current working situation?</p> <p>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</p>
General livelihood		<p>% of people with disabilities who have enough money to meet their needs compared to people without disabilities</p>	<p>Do you have enough money to meet your needs?</p> <p>1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely</p>
General livelihood	<p>Women and men have control over the money they earn</p>	<p>% of people with disabilities who get to make decisions about how to use his/her money compared to people without disabilities</p>	<p>Do you get to decide how to use your money?</p> <p>1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely</p>
Financial services	<p>Men and women with disabilities have access to grants, loans and other financial services on an equal basis with others</p>	<p>% of people with disabilities who know how to access financial services compared to people without disabilities</p>	<p>Do you know how to get financial services such as credit, insurance, grants, savings programmes?</p> <p>1=Yes; 2=No</p>

LIVELIHOOD

Element	Rephrased desirable outcomes	Indicator	Question
Social protection	Men and women with disability access formal and informal social protection measures they need	% of people with disabilities 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 disabilities who are covered by social protection programmes compared to people without disabilities	Do you currently benefit from any social protection programme, such as loss of income through old age, sickness or disability? 1=Yes; 2=No

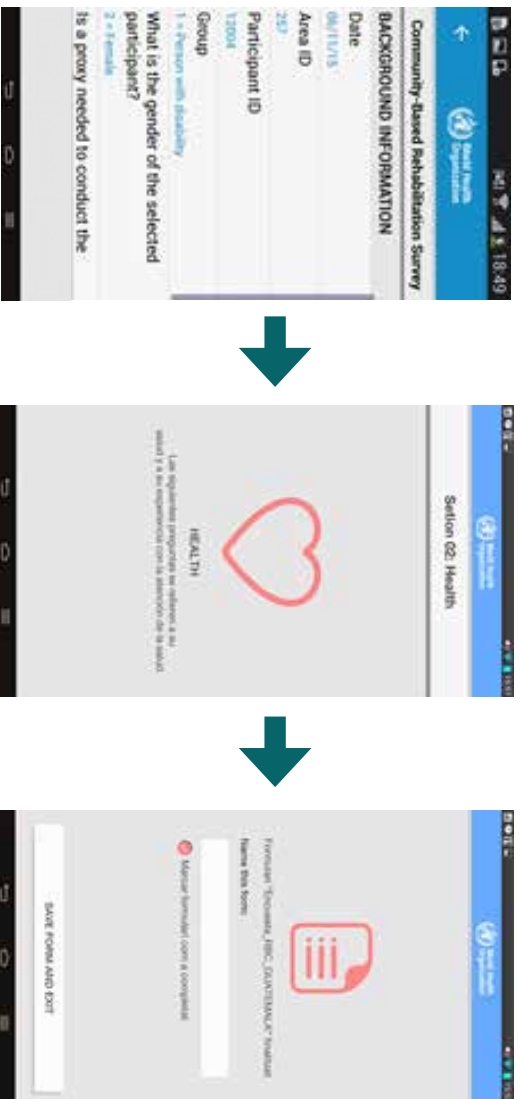
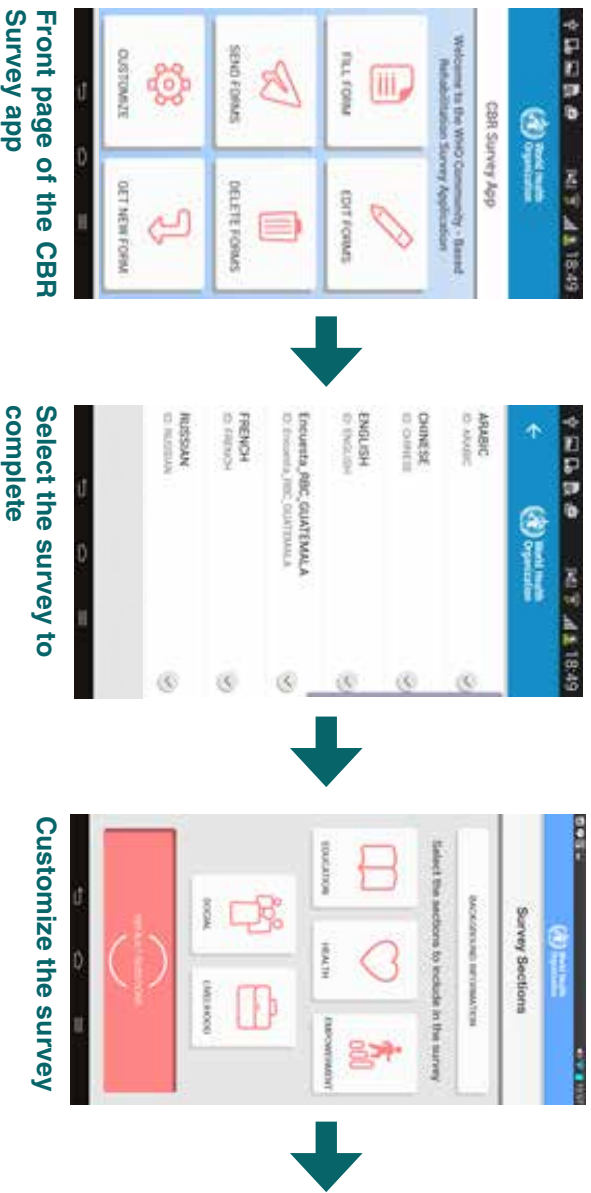
SOCIAL			
Element	Rephrased desirable outcomes	Indicator	Question
General social	Men, women, boys and girls with disability feel valued as community members and have a variety of social identities, roles and responsibilities	% of people with disabilities that feel valued as individuals by members of their community compared to people without disabilities	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 disabilities 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 disabilities who get to make their own decisions about their personal relationships compared to people without disabilities	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 disabilities who get to participate in artistic, cultural or religious activities compared to people without disabilities	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 disabilities who get to participate in mainstream recreational, leisure and sports activities compared to people without disabilities	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 persons with disability are recognized as equal citizens with legal capacity	% of people with disabilities who know their legal rights compared to people without disabilities	To what extent do you know your legal rights? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Justice	Persons with disability access and use formal and informal mechanisms of justice	% of people with disabilities who know how to access mechanisms of justice compared to people without disabilities	Do you know how to access the justice system? 1=Yes; 2=No

EMPOWERMENT			
Element	Desirable outcomes	Indicator	Question
General empowerment	Persons with disability make informed choices and decisions	% of people with disabilities who get to make informed choices and decisions compared to people without disabilities	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	Persons with disability advocate for and/or exercise their rights	% of people with disabilities who know and exercise their rights compared to people without disabilities	Do you think that the policies in your country provide people with disabilities 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 disabilities who have the communication skills to express their wishes and objections effectively compared to people without disabilities	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 disabilities who have a role in shaping their communities to achieve equal opportunities for all compared to people without disabilities	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 disabilities participate in political processes on an equal basis with others	% of people with disabilities who engage in local or national politics and in civil society organizations compared to people without disabilities	Did you vote in the last election? 1=Yes; 2=No
Self-help groups	Persons with disability actively engage in and benefit from self-help groups in local communities, if they choose (inclusive or specific)	% of people with disabilities who actively engage in and benefit from self-help groups compared to people without disabilities	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

EMPOWERMENT			
Element	Desirable outcomes	Indicator	Question
Disabled People's Organizations	<p>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</p> <p>DPOs are influential stakeholders in decision-making</p>	% of people with disabilities who feel that they are adequately represented by DPOs	<p>To what extent do you feel Disabled People's Organizations adequately represent your concerns and priorities?</p> <p>1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely</p>

ANNEX 4: MOBILE APPLICATION

Figure 6. Using the mobile application



- » The **app** can be downloaded at <http://www.who.int/disabilities/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.who.dcp.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/disabilities/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/disabilities/cbr/en/>).

Figure 7. Explanation of background information

The screenshot displays the 'BACKGROUND INFORMATION' section of the WHO CBR app. It includes the following fields and options:

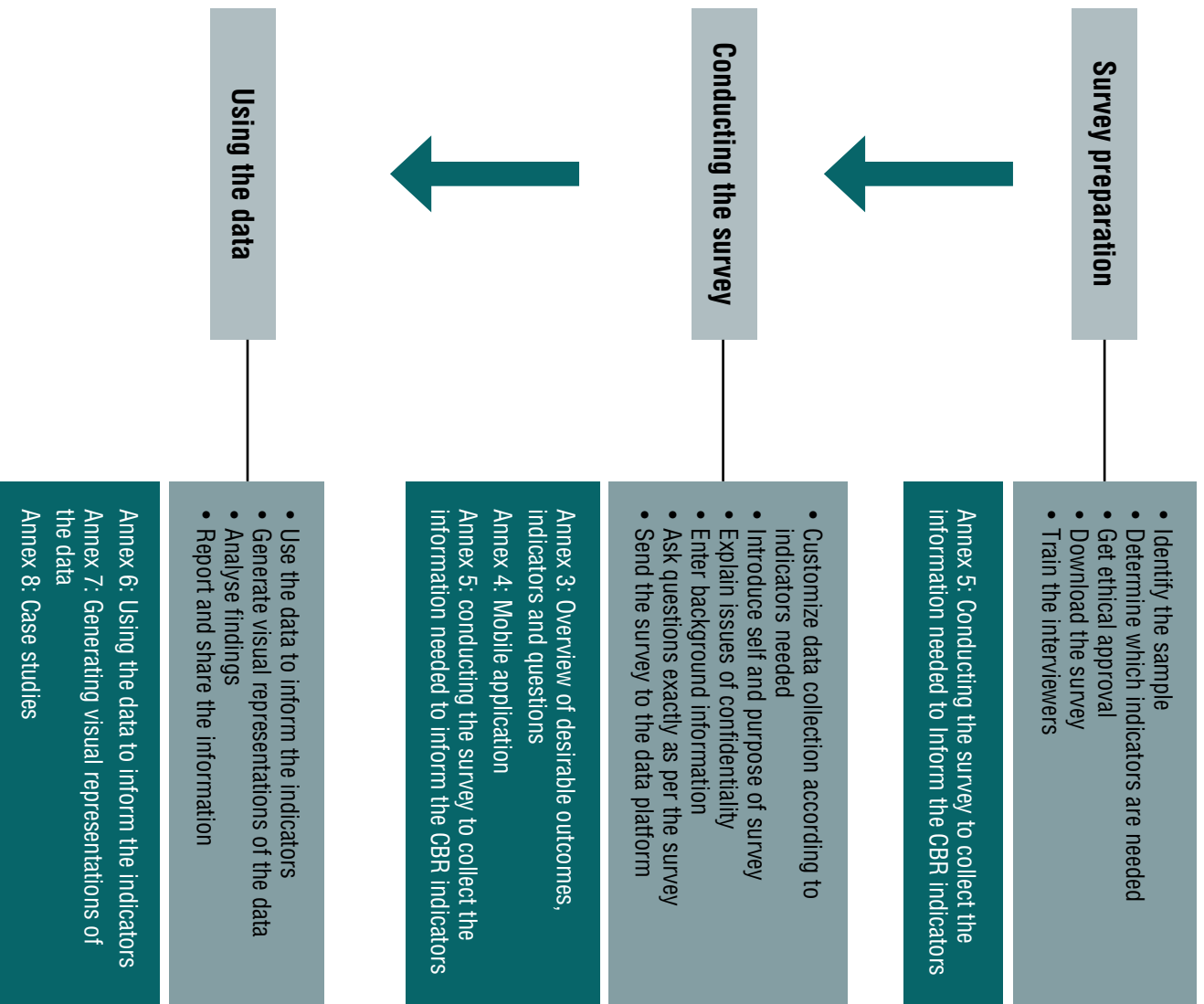
- Date:** 06/11/15
- Area ID:** 257
- Participant ID:** 12004
- Group:** 1 = Person with disability
- Question:** What is the gender of the selected participant?
- Options:** 2 = Female, 1 = Male
- Bottom Buttons:** Go Up, Go To Start, Go To End

Three callout boxes provide definitions:

- Area ID:** This is a name that is the same for each interview done during the survey that can be used to identify the survey when submitted to the data platform
- Participant ID:** A number generated by the interviewer to which all participant's information will be linked.
- Proxy:** A proxy is required if the participant is a child or if they are unable to answer the questions themselves (see the Interviewer Guide for details about what justifies using a proxy).

ANNEX 5: CONDUCTING A SURVEY TO COLLECT THE INFORMATION NEEDED TO INFORM THE CBR INDICATORS

Figure 8. Summary of process of conducting a survey to collect information to inform indicators



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 persons 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
<p>Identify the sample to be interviewed within the community where CBR is implemented</p>	<p>Two groups need to be approached for interviews:</p> <ol style="list-style-type: none"> 1) Adults and children with disabilities,² regardless of whether they are currently participating in CBR or not. 2) Adults and children without disabilities living in the same community, so that a direct comparison between populations is possible. <ul style="list-style-type: none"> - In both groups, a balanced sample of men and women, boys and girls is recommended. - The groups of persons with disability and persons without disability are different, and in light of this the specific approach or criteria used to categorize the groups should be consciously selected and documented. - When determining the size of the sample, 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.
<p>Determine which indicators are needed</p>	<p>WHO recommends always using at least the questions that inform the base indicators. What supplementary indicators are used will depend on the specific CBR strategies and goals in each community.</p> <ul style="list-style-type: none"> - 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.
<p>Get ethical approval for conducting the survey</p>	<p>Ensure ethical approval is acquired according to the regulations of the country, region or institution.</p>

² 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, denoting the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).

INTERVIEWER GUIDE: SURVEY PREPARATION

Steps	What should be done
<p>Confidentiality and mechanisms for follow up</p>	<p>All data must be collected anonymously using a participant ID.</p> <p>For specific research purposes users may want to follow up the same population over time. 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>
<p>Download the mobile app or hard-copy of the survey</p>	<p>An intuitive and easy to use Android app for mobile phones has been developed to collect data with the questions outlined in this manual.</p> <p>The mobile app...</p> <ul style="list-style-type: none"> ... can be downloaded via the WHO CBR website (http://www.who.int/disabilities/cbr/en/). A short video explaining how the app works can also be found on this page. ... works offline; 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 their own or WHO’s Data Collection Platform. <p>Alternatively, a hard-copy version of the survey is available on the WHO CBR website (http://www.who.int/disabilities/cbr/en/). 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>
<p>Train the interviewers</p>	<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>
<p>Automatically reviewing submitted data</p>	<ul style="list-style-type: none"> - 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. - The WHO CBR website will show the collected data about each indicator as graphics comparing persons with disability with other members of the community, as well as comparing boys, girls, men and women.
<p>Customize data collection</p>	<ul style="list-style-type: none"> - 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. - The app can be customized to include additional questions targeting supplementary CBR indicators.



INTERVIEWER GUIDE: SURVEY PREPARATION

Steps	What should be done
Introduce oneself and the reason for the interview	A recommended introduction is: <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>
Explain issues of confidentiality and provide an estimate of how long the interview will take	Duration of interview – 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. Individual rights – The respondent may decline to be interviewed, stop the interview at any point, or refuse to answer some questions. Confidentiality – 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?”</i> Yes/No. 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 9.
Read questions exactly as they are written on the screen	All questions appearing in black should be read out loud All questions appearing in blue should NOT be read out loud. If the participant has difficulty responding, then blue response options can be read out loud. Questions marked with an asterisk (*) imply that multiple response options can be selected.
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.	
Date	The first question of the Background page of the app is to select the date.
Area ID	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.
Participant ID	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.
Group	If the respondent is a person with disabilities, select 1. If the respondent does not have a disability, select 2.
Record the gender of the selected participant	Record the respondent’s sex (male or female) based on observation in the Background section of the app.

INTERVIEWER GUIDE: SURVEY PREPARATION

Steps	What should be done
<p>Decide whether a proxy is needed to conduct the interview</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>Record the participant's age</p>	<p>Enter the participant's age in the Background page of the app.</p>
<p>Probe if respondent has difficulties answering</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"> - misinterprets or does not understand the question - cannot make up his or her mind, or - says that they don't know the answer. <p>Probing techniques include to:</p> <p>Repeat the question – The respondent may come up with the answer if they hear the question a second time.</p> <p>Pause – This gives the respondent time to collect their thoughts.</p> <p>Repeat the respondent's reply – This is often an effective way of having the respondent reflect on the answer they have just given.</p> <p>Use neutral probes – 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>If probing does not lead to an answer, use the "Not applicable", "Don't know" or "Refuse" response options as appropriate</p>	<p>"Not applicable" – Some questions may not apply or be relevant for the respondent. In this case, select this option.</p> <p>"Don't know" – 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>"Refuse" – 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>



Boxes shaded in grey denote those that inform base indicators.

HEALTH COMPONENT

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/disabilities/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
H01	In general, how would you rate your health today? 1=Very good; 2=Good; 3=Neither poor nor good; 4=Poor; 5=Very poor	Respondents should evaluate their general health including physical and mental health.
H02	On your last visit to a health-care provider, to what extent were you satisfied with the level of respect you were treated with? 1 (Not at all); 2; 3; 4; 5 (Completely)	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.
H03	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	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.
H04	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	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.
H05	In the last 12 months, has there been a time when you needed health care but did not get that care? 1=Yes; 2=No; 3=No need for health care in the past 12 months	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.
H06	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 / 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	If the respondent’s answer is not listed in the response options, select “Other”. Record all reasons that the respondent indicates. The cost of visit (response option 2) can refer to the medical fees, transit costs or any others costs associated to the visit.

HEALTH COMPONENT

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/disabilities/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	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; 3; 4; 5 (Completely)	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	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; 2=No; 3=No need for rehabilitation services in the past 12 months	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	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	The cost of visit (response option 2) can refer to medical fees, transit costs or any others costs associated with the visit. If the respondent’s answer is not listed in the response options, select “Other”. Record all reasons that the respondent indicates.
H10	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 braces? 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	Mobility aids are, for instance, a cane, crutch, wheelchair, walking frame, prosthesis or orthopedic device, among others. Aids for self-care are, for instance, hand braces, arm braces or grasping tools, among others.



HEALTH COMPONENT

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/disabilities/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
H11	<p>Do you use any visual aids, such as glasses or a white cane?</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>Visual aids are, for instance, glasses or books with large print, a white cane or guide dogs, among others.</p>
H12	<p>Do you use anything to help you hear or communicate better?</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>Hearing or communication aids are, for instance, usual hearing devices, a visual or vibrating alarm, a cochlear implant or a voice amplifier, among others.</p>
H13	<p>Do you know how to keep your assistive device in good working condition?</p> <p>1=Yes; 2=No; 3=Not applicable</p>	<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.</p>



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/fools?round=mics3>) and one from the Model Disability Survey (<http://www.who.int/disabilities/data/mds/en/>). **Response options in blue must not be read by the interviewer aloud.**

Item	Question and response options	Explanations
E01	<p>What is the highest level of education you have achieved, or are working to achieve?</p> <p>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”.</p> <p>The categories of educational levels vary across countries and country-specific guidance for how to complete this question is needed.</p>
E02	<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>	<p>A “regular institution” refers to mainstream schools, while “specialized institutions” refer to schools or facilities organized specifically for students with disabilities or special needs.</p> <p>If the respondent attended more than one type of instruction, select all that apply.</p>
E03	<p>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?</p> <p>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>Do you participate in learning opportunities to improve your skills for everyday life or work?</p> <p>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>To what extent does it fit your needs?</p> <p>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/disabilities/data/mds/en/>). **Response options in blue must not be read aloud by the interviewer.**

Item	Question and response options	Explanations
L01	<p>What is your current working situation?</p> <p>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. If their response does not match an option, select "Other".</p>
L02	<p>Do you have enough money to meet your needs?</p> <p>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>Do you get to decide how to use your money?</p> <p>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>



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/disabilities/data/mds/en/>). **Response options in blue must not be read aloud by the interviewer.**

Item	Question and response options	Explanations
L04	Do you know how to get financial services such as credit, insurance, grants, savings programs? 1=Yes; 2=No	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.
L05	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 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.
L06	Do you know how to get social protection against loss of income resulting from old age, sickness or disability? 1=Yes; 2=No	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.



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/disabilities/data/mds/en/>) and from the WHO Quality of Life-BREF (http://www.who.int/substance_abuse/research_tools/whogqlbref/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	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; 3; 4; 5=Completely	This includes the respondent's opinion on people showing them consideration and treating them with respect.
S02	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; 3; 4; 5=Completely	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	Do you get to make your own decisions about your personal relationships, such as friends and family? 1=Not at all; 2; 3; 4; 5=Completely	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	Do you get to participate in artistic, cultural or religious activities? 1=Not at all; 2; 3; 4; 5=Completely	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	Do you get to participate in community recreational, leisure and sports activities? 1=Not at all; 2; 3; 4; 5=Completely	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.

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/disabilities/data/mds/en/>) and from the WHO Quality of Life-BREF (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
S06	To what extent do you know your legal rights? 1=Not at all; 2; 3; 4; 5=Completely	This means legislation, regulations and standards including laws, customary law, religious law, international laws and conventions that govern the administration of justice.
S07	Do you know how to access the justice system? 1=Yes; 2=No	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/whogqbref/en/).

Item	Question and response options	Explanations
M01	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; 3; 4; 5=Completely	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	Do you think that the policies in your country provide people with disabilities equal rights as other people? 1=Not at all; 2; 3; 4; 5=Completely	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	Are you satisfied with your ability to persuade people of your views and interests? 1=Not at all; 2; 3; 4; 5=Completely	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	Do you get to influence the way your community is run? 1=Not at all; 2; 3; 4; 5=Completely	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	Did you vote in the last election? 1=Yes; 2=No	This question targets whether the respondent has voted or not in the last election; no further information should be requested.
M06	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	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	To what extent do you feel Disabled People's Organizations adequately represent your concerns and priorities? 1=Not at all; 2; 3; 4; 5=Completely	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 6: 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 disabilities 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 disabilities (56 women and 78 men) 153 people without disabilities (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 disabilities		Without disabilities	
	Yes	No	Yes	No
Men (78)	30	48	59	13
Women (56)	16	40	65	16
Total	46	88	124	29

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 disabilities, all people without disabilities, 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 disabilities who answered "Yes" (because this indicator shows how many people do know). For example, to calculate the percentage of **women with and without disabilities that answered "Yes"** (the 'part' = 16 and 65 respectively), the whole would be the complete number of women with disabilities (56) and all women without disabilities (81). The formula would therefore be used as follows:

Women with disabilities

$$\frac{16}{56} \times 100 = 28.6\%$$

Women without disabilities

$$\frac{65}{81} \times 100 = 80.2\%$$

The indicator would therefore be:

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

» The same calculation can be repeated for men with disabilities and for men without disabilities. Alternatively, to compare the total number of people with disabilities to the total number without disabilities that answered "Yes", simply add the number of men and women in each category that answered "Yes" (46 with disabilities 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 disabilities) (134 and 153 respectively).

People with disabilities

$$\frac{46}{134} \times 100 = 34.3\%$$

People without disabilities

$$\frac{124}{153} \times 100 = 81\%$$

The indicator would therefore be:

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



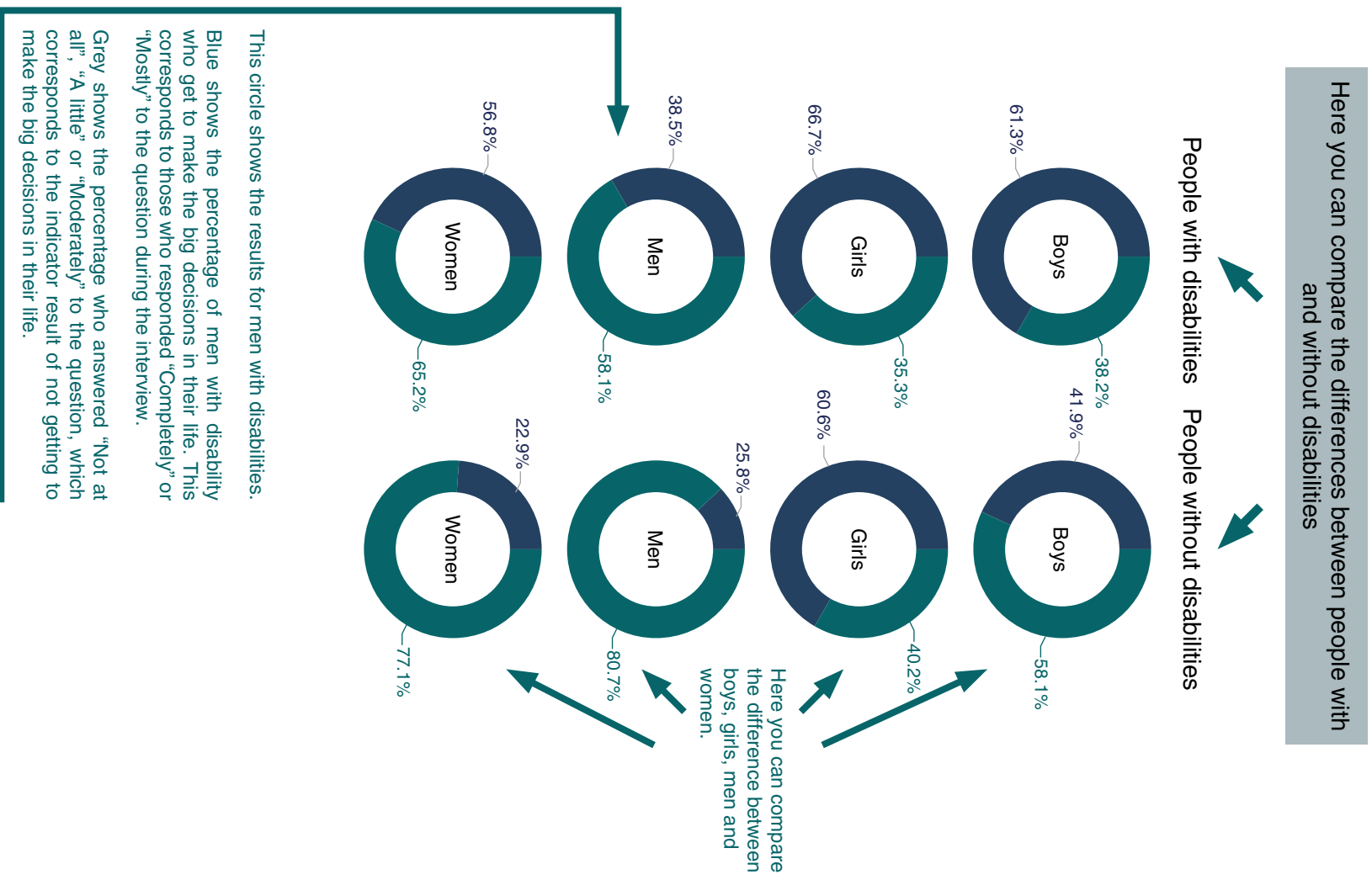
ANNEX 7: GENERATING VISUAL REPRESENTATIONS OF DATA

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 disabilities and those without disabilities 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 disabilities who get to make informed choices and decisions compared to those without disabilities”, 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



ANNEX 8:

CASE STUDIES

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 persons 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 persons 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 persons 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 persons 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 persons with disability in the town have significantly less access to medical care than persons without disability (Graph 1). This strongly supported the assumption prior to data collection that persons with disabilities in the area face barriers in accessing medication. Additionally, data from the base indicator on livelihood showed that persons 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.

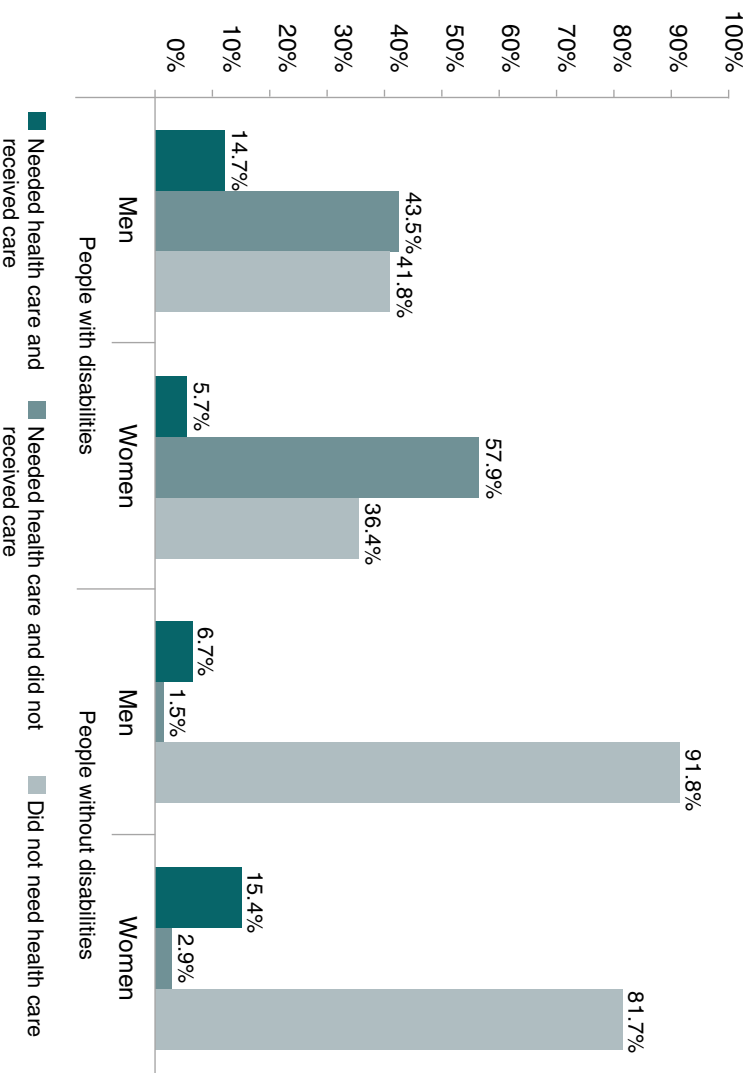
The Director of the District Health Services then compared the data collected on access to health care and finances in her town with national data on these topics, available from the WHO CBR data collection platform, and concluded that the results were similar across the country. She contacted her colleagues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

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

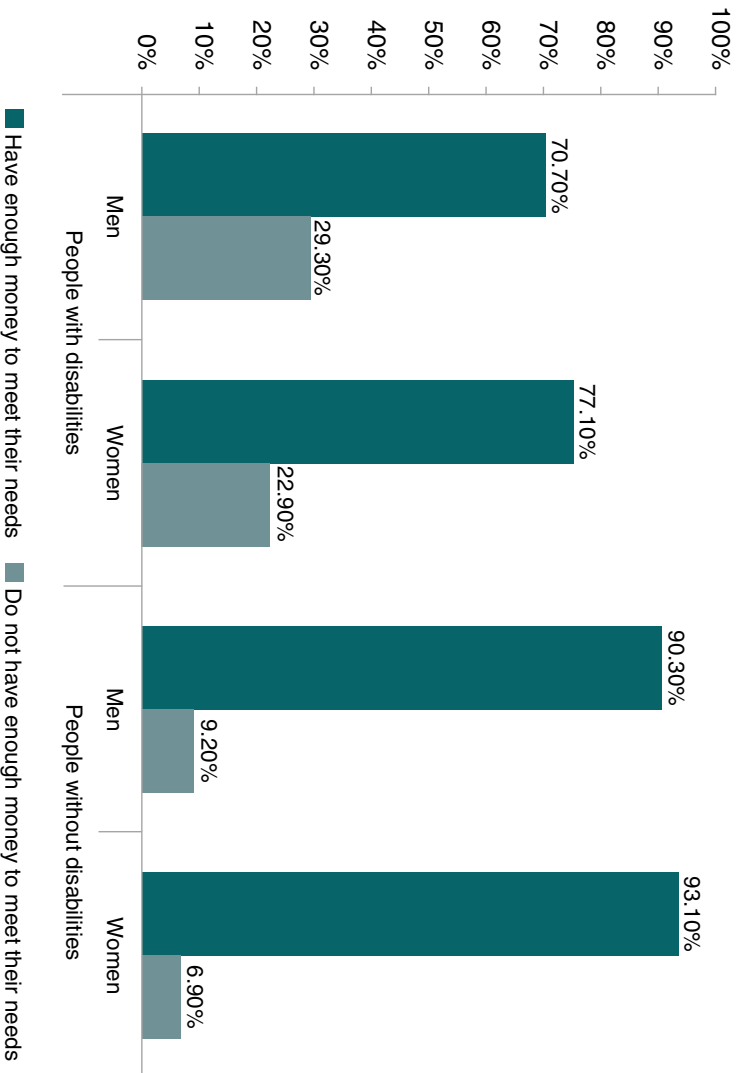


The district rehabilitation team plans to repeat the survey after 1 year to see whether their efforts at a local level led to improvements, and to then compare their results with other teams in the country.

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 persons 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 persons 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 persons 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.

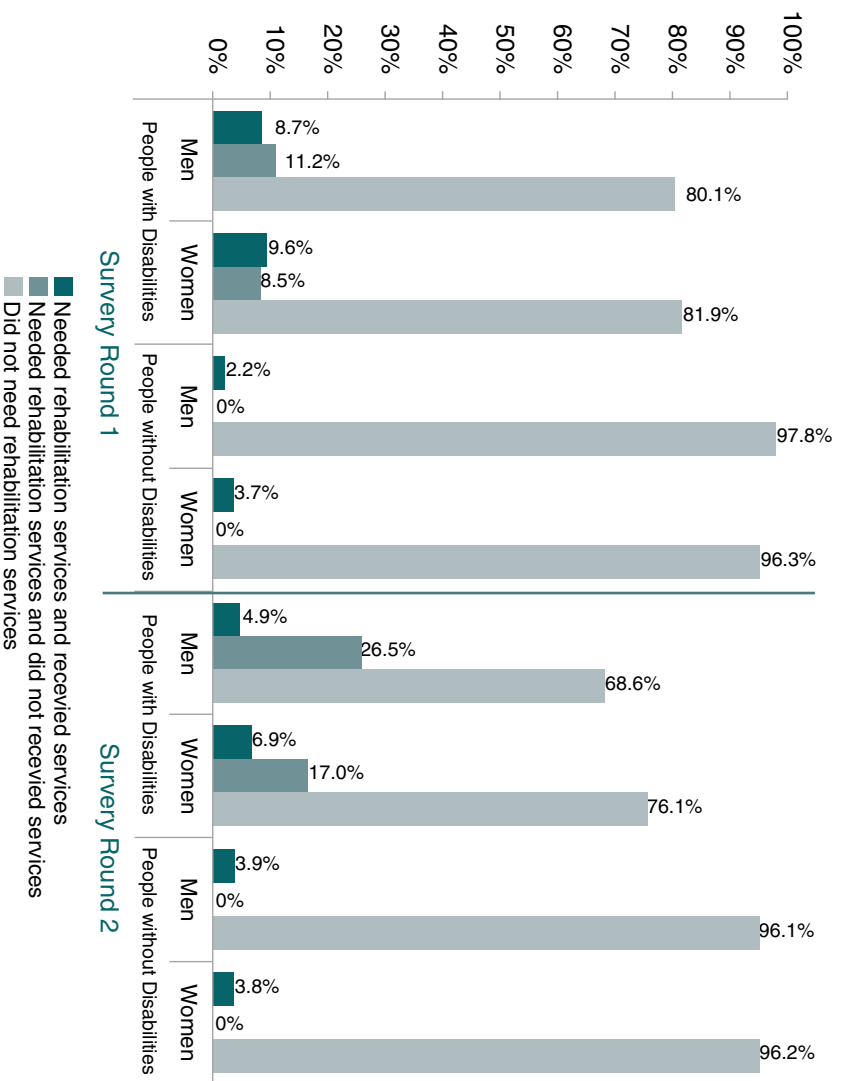
The ministry stated that they do not have sufficient funds to implement the action plan beyond the first year. Therefore, the CBR team decided to approach the Ministry of Health for further financial support for the rehabilitation aspect of their work. To this ministry they presented a summary of the 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 persons with disabilities 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 disabilities. 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 disabilities.

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

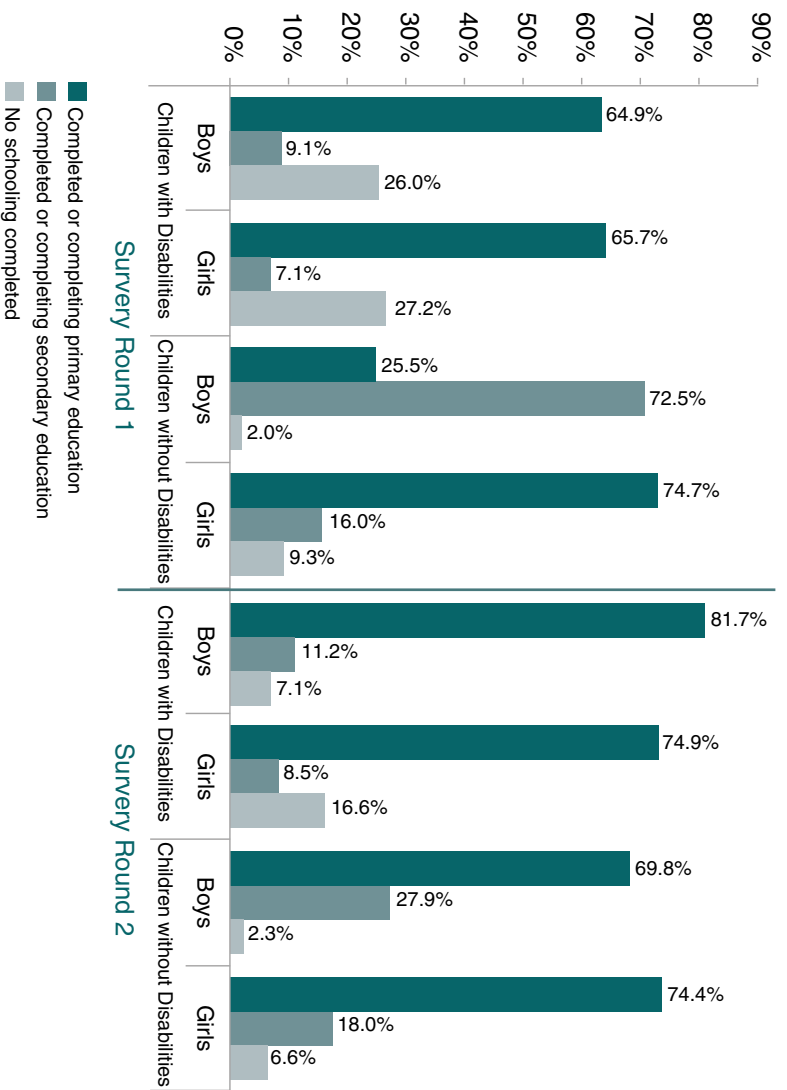
As a consequence of this result, the CBR coordinator decided to organize visits to primary health facilities and to conduct interviews with some parents to better understand the reasons for the worse health status of children with disabilities. Additionally, it was decided that in future, data collection 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.

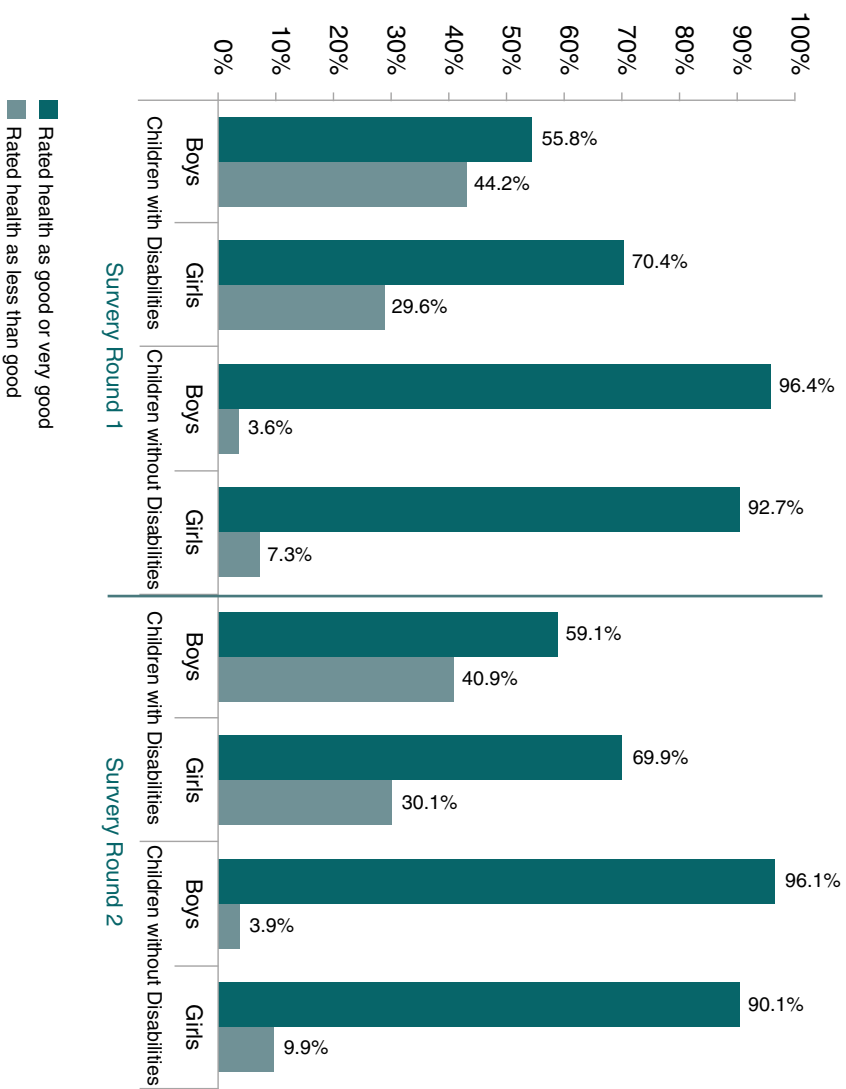
The CBR coordinator, along with coordinators of other CBR initiatives in the country and local school authorities, used this information to lobby the Ministry of Education to provide ramps and organized disability awareness training sessions with local teachers.



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 disabilities completing or having completed schooling in comparison to children without disabilities is presented for the first and second round of the survey.



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 9: EXAMPLE CONSENT FORM

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 [center 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 persons with disability and persons 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.

Read by participant	Agreed	Interviewer	Refused

Signatures

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

Name:		Sign:	
Parent/Guardian:		Sign:	

ANNEX 10: GLOSSARY

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.¹

Base CBR Indicators

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

Community-based rehabilitation (CBR)

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

CBR matrix

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

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.²

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.²

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 persons with disability.¹ 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.²

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).¹



Educational certificate

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

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.²

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.⁷

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.⁹

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.¹²

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.¹⁰

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.³

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.¹

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.⁸

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.¹¹

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.¹

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).¹

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).¹

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).¹

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.¹

Self-help groups

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

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.²

Social protection programmes

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

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.²

Specialized (educational) institution

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

WHO Global Disability Action Plan 2014-2021

A report endorsed by the 67th 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.⁵

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.⁴



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