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Developing and testing a set of global indicators for monitoring Community-Based Rehabilitation

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Abbreviations

App	Application
CBR	Community-Based Rehabilitation
CRPD	Convention on the Rights of Persons with Disabilities
DPO	Disabled People’s Organization
ICF	International Classification of Functioning, Disability and Health
IDDC	International Disability and Development Consortium
ILO	International Labour Organization
INGO	International Non-Governmental Organization
LFA	Logical Framework Approach
NGO	Non-Governmental Organization
OECD	Organisation for Economic Co-operation and Development
PSM	Propensity Score Matching
UN	United Nations
UNESCO	United Nations Educational Scientific and Cultural Organization
UNICEF	United Nations International Children’s Emergency Fund
WHO	World Health Organization

Introductory Summary

1. Disability

Disability is a diverse concept that integrates the fields of health, social sciences, development, and human rights. Based on 2010 population estimates, the World Health Organization (WHO) estimates the global prevalence of disability to be about 15% of the world's population [1]. The concept of disability has evolved over time and is now considered to be part of the human condition, with every person experiencing some level of disability over their lifetime; whether it is temporary, permanent or associated with the onset of old age [1]. The current definition of disability according to the International Classification of Functioning, Disability and Health (ICF) defines disability as: "an umbrella term, covering impairments, activity limitations, and participation restrictions" and "a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives" [2]. This implies that disability arises from the interaction of health conditions and contextual factors.

In recognition of the significance of disability as a health, social, economic and human rights issue, the United Nation's (UN) called on member states to fulfill their legal obligation to promote and protect the rights and freedoms of all people with disabilities through the 2006 *Convention on the Rights of Persons with Disabilities* (CRPD) [3, 4]. Despite the 163 signatories, the world's population with disabilities continues to face stigma, discrimination, barriers to equal participation and lack of appropriate services [5]. People with disabilities face worse health outcomes, exclusion from school, have lower educational achievements, are at greater risk of poverty, and are less likely to participate in community life in comparison to people without disabilities [1, 6].

These disparities are even more pronounced in resource-constrained settings and lower-income countries. This is of great relevance as it is estimated that 80% of people with disabilities live in lower-income countries [3]. Currently, the health and social systems of many low- and middle-income countries do not meet the requirements for such care, as the long-term nature of most disabilities requires specially trained personnel, available referral systems and sustainable services [7]. Since the late 1960's there has been discussion in the field of disability regarding the inequality in service delivery experienced between low-, middle- and high-income countries and between urban and rural areas. The main challenges that need to be addressed to help reduce the disparities between people with and without disabilities, particularly in low-income and resource-constrained settings, include: (i) stigma and lack of awareness, (ii) limited human and material resources, (iii) insufficient infrastructure [7].

2. The Origins of CBR

As the concept of disability has evolved over time, so too have the approaches for caring for people with disabilities. One of the greatest shifts occurred in the 1970's when the deinstitutionalization of people with disabilities gained momentum. With this change, people with disabilities entered community life [8]. This led to an increase in the need for services in the community and the realization of the disproportional distribution of healthcare and rehabilitation resources, leaving people with disabilities in many low- and middle-income regions without access to required services [9, 10].

Starting in the 1970's, the WHO began to recognize this discrepancy and to develop approaches to meet the basic needs of people with disabilities to ensure their inclusion [11, 12]. The WHO realized that to do this, there was a need to provide interventions and training at the individual, family, and community level and to use existing local infrastructure. The utilization of community resources was recognized as a cost-effective way to organize care, especially in low-resource settings [11, 12].

In the 1976 the WHO *Disability Prevention and Rehabilitation* presented these concepts grouped together under the term "Community-Based Rehabilitation" (CBR). It presents CBR as a novel, common-sense approach to facilitate basic rehabilitation services in low-income areas [12]. The 1978 *Alma Ata Declaration on Primary Health Care* expands slightly on this, outlining the importance of the inclusion of rehabilitation into general health care systems, with the goal of making essential health services available to everyone. It further emphasized the importance of using community resources as a cost-effective and feasible way to organize health systems [11]. These early initiatives drew some global attention to the concept of CBR, but it wasn't until the 1980's that CBR gained international recognition.

3. The Current Understanding of CBR

Since its international uptake in the 1980's, CBR has evolved into a multi-sectoral approach working to equalize opportunities and include people with disabilities in all aspects of community life. It is defined as "a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities" [13]. CBR is promoted by various intergovernmental organizations – including the WHO, United Nations Educational, Scientific and Cultural Organization (UNESCO), and International Labour Organisation (ILO) – as the intervention of choice in low-resource settings to promote and support the inclusion of people with disabilities in their communities; and is now implemented in over 90 countries [14].

In an effort to synthesize global perspectives on CBR, the WHO developed their *Community-Based Rehabilitation Guidelines* in 2010 which have since become accepted as a conceptual framework for CBR [15]. With these Guidelines, the WHO recognized that no single model of CBR is appropriate for the whole world, and further emphasized the need for a common global framework for monitoring CBR in line with the CRPD [15, 16]. The CBR Guidelines offered recommendations on strengthening the capacity of mainstream and specific services to include people with disabilities in accessing the benefits of the health, education, livelihood and social sectors and enhance empowerment [15, 16]. The CBR Guidelines visualized these possible

CBR activities into the CBR Matrix (Figure 1), which presents five components, each with five corresponding elements. The goals of each of the components and elements of CBR Matrix are also provided in the Guidelines, presented as 174 bullet points called "desirable outcomes" [15].

The CBR Guidelines, and the breakdown of the activities and goals of CBR into 5 components, 25 elements, and 174 desirable outcomes, help to present the complexity of CBR activities and diversity of stakeholders in a comprehensible manner [15, 16].

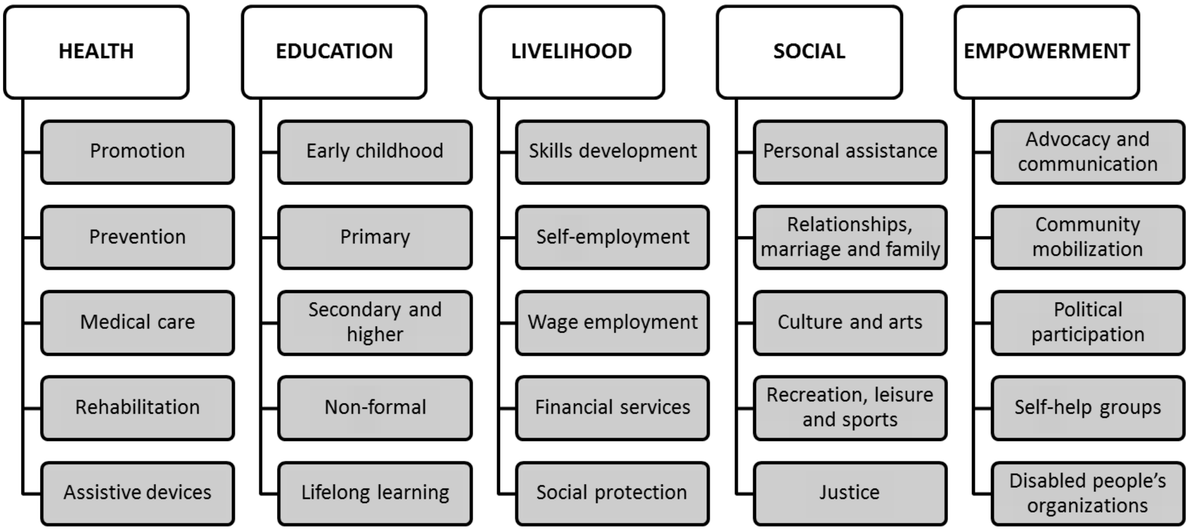

Figure 1: The CRB Matrix

4. Motivation for the Project

A significant challenge faced by the CBR sector in promoting and advocating for a broader implementation of CBR is the ability to demonstrate internationally comparable, quantitative results [16-19]. The lack of standardized measures limits the generated evidence and the comparability across settings [16, 19-21]. The wide scope of CBR activities, covering health, education, livelihood, social life and empowerment, is further broadened through the various implementing bodies involved in CBR, including people with disabilities themselves, their families and communities, and the relevant governmental and non-governmental sectors [13, 22, 23]. It is due, at least in part, to this extensive definition that reliable and internationally comparable data to monitor and evaluate CBR is scarce [17-19]. The complexity of CBR, and often limited resources available in the field, lead to challenges in research attempting to quantify its effectiveness [17, 18, 24, 25].

As part of this ongoing work, the WHO set strengthening CBR, particularly through the collection of relevant and internationally comparable data for monitoring and evaluation, as one of the three objectives of its *Global Disability Action Plan 2014–2021* [14]. It emphasized that reliable data is essential for informing policy, allocating resources and guiding implementation. This call for action from the WHO was the motivation for this PhD project with the goal of developing and testing a set of global indicators for monitoring CBR. To accomplish this, the WHO instigated a collaboration between the WHO, the University of Munich (LMU), the International Disability and Development Consortium (IDDC) and the charity organization

CBM (formerly known as Christoffel-Blindenmission). The partnership with the LMU ensured a strong academic foundation to guide this project and working with the IDDC and CBM provided the opportunity for cooperation with a wide range of CBR stakeholders to share their expertise and field experiences from the global CBR community.

The working definition of monitoring adopted for this project was: a descriptive process that provides information on the state of a program or project at a given time, relative to its respective targets and outcomes [16, 26]. Monitoring of programs, followed by evaluation, is essential to inform decisions such as continuation, alteration or cessation of CBR programs, as well as to provide evidence for its effectiveness [26].

5. Developing and Testing the Indicators

The overall objective of this PhD project was to develop and test a set of indicators capable of monitoring CBR in order to provide an overview of the extent to which CBR facilitates changes in the lives of people with disabilities in different world regions. The specific aims were to develop indicators that:

(1) are standardized – they are independent of program activities, location or specific resources
(2) are inclusive – they are applicable to people with disabilities and people without disabilities in order to identify differences between the groups
(3) receive approval from the CBR community – they are developed through international collaboration of stakeholders and involve a consensus process.

The following sections outline the steps which were taken to develop and test the indicators. Please note that the sections regarding the development process are a summary of what has already been published in Publication 1 of this PhD [16].

5.1 Preparatory Work

Aim: To examine the CBR literature, to identify relevant pre-existing indicator projects and to determine the extent to which the previous work aligns with the CRPD.

Process: An extensive internet search was used to identify disability and population health indicators from initiatives around the world, including indicators from the following projects: Human Development Index, Millennium Development Goals, WHO Model Disability Survey, UNICEF Multiple Indicator Cluster Survey 4, WHO Global Disability Action Plan, WHO Core Health Indicators and the Zero Project [16]. Since no CBR-specific indicators exist, the CBR Guidelines desirable outcomes were also included to give an overview of CBR project goals, and since indicators following the CBR Matrix have been proposed for monitoring CBR in the past [16, 27, 28].

The indicators from the various projects and the CBR Guidelines desirable outcomes were mapped against the articles of the CRPD to facilitate comparison and determine content alignment. This linking showed that the CBR Guidelines desirable outcomes closely follow the CRPD, while many of the other projects lacked coverage of specific sections of the CRPD [16].

Result: Using indicators from pre-existing projects would not align sufficiently with the CRPD or the aims of CBR. Therefore, the CBR Guidelines desirable outcomes were to be used as a basis for the CBR indicators, as they align with the CRPD and are internationally accepted as conceptual framework for CBR [15, 16].

5.2 Indicator Framework

Aim: To use a framework to determine how to convert the CBR Guidelines desirable outcomes into indicators capable of monitoring CBR.

Process: The CBR Guidelines desirable outcomes are a list of goals that follow the CBR Matrix [15]. Other than their content following the CBR Matrix, the formulation of the desirable outcomes does not have an underlying structure. In order to use them as a basis for the indicators, they needed to be adapted to follow a standardized framework [16].

Program theory includes the logical framework approach (LFA) which presents four types of indicators that 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” [26]. Namely, these are inputs into an activity, outputs of the activity, outcomes of the activity, and impacts of the activity. Specifically, inputs are part of the implementation of an intervention, while outputs are the products, capital goods and services which come as a direct result of inputs. Outcomes are the expected or achieved short-term and intermediate-term effects of an intervention’s outputs that are observed as behavioral, institutional and societal changes, while impacts are the long-term effects or goals of an intervention [26, 29].

The CBR Guidelines desirable outcomes, despite being labelled as outcomes, are presented as inputs, outputs, outcomes and impacts [16]. It was decided that in the practice of CBR, outcome results would be the most effective as CBR indicators as they can be developed to concentrate on middle-term outcomes at the community level. Furthermore, inputs and outputs do not provide an indication of the extent to which a program is effectively achieving its goals, and impacts are long-term effects that are beyond the scope of attributions to a CBR intervention, as in some cases they may reflect societal change [26, 29].

Result: The LFA will be used to develop outcome indicators from the CBR Guidelines desirable outcomes that are independent of program activities, location or specific resources and that can be applied to people with disabilities and people without disabilities in order to identify differences between the groups [16].

5.3 Stakeholder Consensus

Aim: To organize a consensus process with the global CBR community to develop an alpha version of the outcome indicators and corresponding set of survey questions to collect data to inform the indicators, and to develop a method of data collection that could be used in low-resource settings.

Process: A consensus workshop took place over two days at the WHO in Geneva including 12 experts from the global CBR community including members of the IDDC and of CBM.

During this workshop the CBR Guidelines desirable outcomes were converted into outcome indicators.

The first step was to categorize each desirable outcome as an input, output, outcome, or impact using the LFA. Next, a content analysis on each desirable outcome was conducted to formulate it as an outcome, independent of specific CBR objectives, sensitive to changes at the person level and suitable for comparisons across regions. In the third step, desirable outcomes that could not be revised according to the above-mentioned criteria were excluded. In the last step, the most adequate re-formed desirable outcomes in terms of feasibility and reliability of information delivered was selected per component and element of the CBR Matrix [16].

For data collection, a survey was developed to inform the indicators. Indicators were operationalized into a question or a response option of an overarching question [16]. The use of standardized questions from validated questionnaires or surveys was preferred and when no such standardized question was available, new questions were developed through a similar consensus process as was used for the indicator development [16].

To further support data collection, a mobile phone application (app) for Android phones was developed to provide an easy-to-use method for data collection. The app is free to download from Google Play ("WHO CBR Survey") and works offline to avoid the need for mobile data or WIFI. Interviewers use the touchscreen to navigate and to enter demographic data and the responses to the survey questions as multiple choice responses. After completion, the data is temporarily stored in the mobile phone and interviewers have the option to either submit the collected data to a selected e-mail address in the form of an excel spreadsheet or anonymously to the WHO secure server [16, 29].

Result: An alpha version of the indicators containing 52 indicators and 51 corresponding survey questions covering all aspects of the CBR Matrix, an Android mobile phone app that is free to download and works offline for survey data collection [16].

5.4 Pilot Testing and Expert Survey

Aim: To test the acceptability and feasibility of the indicators, questions, and data collection method to determine the complete first set of CBR indicators.

Process: Pilot testing was carried out in three countries representing different world regions and included 801 participants: Guatemala (n=303), Egypt (n=237), and China (n=260). Both survey participants and interviewers were asked to provide feedback through focus groups on the survey and the app. Focus groups in Guatemala, the first country carrying out the pilot testing, revealed problems that were then addressed before the pilots in Egypt and China [16]. An overarching problem was the high complexity of some questions and difficulties with the response options. Neither survey participants or interviewers raised issues regarding using the mobile phone app for data collection [16, 29].

The expert survey included 31 representatives from all WHO world regions and diverse professional backgrounds. In order to decrease the number of indicators and questions, experts were asked via online survey to rank the alpha indicators by relevance and the questions on feasibility. Per component and element of the CBR Matrix the indicator ranked as the most relevant by the majority of experts was selected for the complete first set [16].

In both the pilot testing and the expert survey, the issue was raised that the survey was too long and that it might not be realistic to carry out the whole survey due to time constraints. It was therefore decided to break the indicators down into two sets: “base indicators” which are broad and should be used in all data collection activities to ensure comparability, and “supplementary indicators” which can provide more specific coverage and can be selected depending on the specific CBR goals and strategies of a program. Furthermore, it was made possible to do this customization in the mobile phone app [16, 29].

Result: Thirteen base CBR indicators with eight corresponding questions and 27 supplementary indicators with 30 corresponding questions were selected. Publication 1 [16] of this PhD describes in detail all phases of the development process of the WHO CBR Indicators. Additionally, the Supplementary Publication [29] of this PhD presents the indicators, the recommended data collection procedures, and the reporting strategy as a “how-to” guide for using the indicators in the field.

5.5 Implementation

Aim: To use the complete first version of the indicators and their corresponding survey and app in a real-world implementation.

Process: The implementation was conducted in partnership with the WHO, CBM and the government of Vietnam as part of its review of its *National Rehabilitation Plan 2014-2020*, which includes CBR. Specifically, the aim was to collect data to compare differences in the lives of people with disabilities to those without disabilities in provinces where CBR is implemented to provinces where CBR is not, in order to guide government organizations in this review process to support informed decision-making regarding the continuation, alteration or cessation of CBR as part of the national plan.

The full WHO CBR survey including the base and supplementary indicators for health, education, livelihood, social and empowerment were collected in provinces representing different levels of CBR coverage (full, partial or no coverage). People with disabilities were identified prior to the survey by government records and a person without disability of same age and similar gender was selected by convenience sample from a neighboring household for comparison. Data was collected anonymously by the team of five trained interviewers per province via the WHO CBR Survey app [25, 30].

Result: Data was collected from 899 respondents in three Vietnamese provinces: Huế (n=302, where CBR is fully implemented), Thái Bình (n=297, where CBR is partially implemented) and Hòa Bình (n=297, where CBR is not implemented). Overall, the sample consisted of 46.4% female respondents and 49.7% people with disabilities, with these proportions similar between provinces. The results of the survey were presented to the Vietnamese Ministry of Health in the form of a report with intuitive graphics. For the greater CBR and scientific community, the results were made available in the form of manuscripts for peer-reviewed journals demonstrating possible methods for quantitative analysis.

Publication 2 [25] of this PhD presented propensity score matching (PSM) as a potential statistical method to evaluate cross-sectional CBR data, as randomization is not possible due to the inclusive nature of CBR and limited resources mean that longitudinal data collection is rarely feasible. In the unmatched sample, significant differences between groups were found. PSM successfully adjusted for bias in all available covariates in the matched sample. A paired t-test compared the outcome of community inclusion between CBR and non-CBR participants for both the matched and unmatched samples, with CBR participants found to have significantly worse community inclusion scores than non-CBR participants. This result did not differ between the matched and unmatched samples [25]. These counter-intuitive results could be explained by many factors including that the use of cross-sectional data meant that the causal relationship between CBR implementation and social inclusion could not be determined, and that the outcome of community inclusion, though the ultimate goal of CBR, was not the direct target of the CBR program where the data was collected. This publication concludes that PSM should be considered when analyzing cross-sectional CBR data in order to reduce bias, especially for international comparisons where differences between populations may be greater [25].

Publication 3 [30] of this PhD used multivariate linear regression and a social inclusion score created from the indicators to estimate which predictors (namely demographic, health, education, livelihood, or empowerment) had the greatest association with the social inclusion of CBR participants, in comparison to the general population. The analysis found that livelihood and empowerment predictors had the strongest association with social inclusion of CBR participants, while livelihood predictors had the strongest association for the general population. This publication highlights the need for CBR programs to emphasize livelihood and empowerment activities in order to increase the social inclusion of people with disabilities [30].

6. Conclusion

The WHO CBR Indicators offer a standardized approach to collect comparable CBR data anywhere in the world. These indicators can be used independent of program activities, location or specific resources, are applicable to people with disabilities and people without disabilities to identify differences between the groups, and were developed through international collaboration of CBR stakeholders (PhD Publication 1 [16]).

These indicators examine differences in health, education, social life, livelihood and empowerment and are broken down into two subsets: base indicators which are broad and should be used in all data collection activities to ensure comparability, and supplementary indicators which can provide more specific coverage, and can be selected depending on the specific CBR goals and strategies of a program [16]. Furthermore, the WHO CBR Indicators provide a quick and simple data collection strategy through the accompanying survey questions to inform the indicators, the presentation of the survey questions in the form of an Android mobile phone app, a user's manual outlining the data collection procedures and the ability to submit collected data directly from the mobile phone app to the researcher's email address in the form of an excel spreadsheet (PhD Supplementary Publication [29]).

Data collection can be done by CBR managers, CBR workers, researchers, funding agencies and/or any other interested bodies, at any stage of CBR implementation [29]. They can assess the current situation using cross-sectional data and monitor the difference CBR is making in the lives of people with disabilities over time using longitudinal data. Through the implementation of the indicators and the publications outlining some possibilities of how to use the data (PhD Publication 2 [25] and Publication 3 [30]), there is encouragement that the uptake of the indicators in the field will grow to enable informed decision-making regarding continuation, alteration or cessation of CBR programs.

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Publication 1

RESEARCH ARTICLE

Development of indicators for monitoring Community-Based Rehabilitation

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Abstract

Background

Community-Based Rehabilitation (CBR) is a multi-sectoral approach working to equalize opportunities and include people with disability in all aspects of community life. Reliable and internationally comparable data needed to monitor and evaluate CBR are scarce, partially due to the absence of standardized indicators. The objective of this manuscript is to describe the collaborative development process which led to the World Health Organization's (WHO) recently launched set of standardized CBR outcome indicators.

Methods

The WHO's CBR Guidelines recognize CBR as a comprehensive and multi-sectoral strategy, and were therefore used as the starting point for the development of the indicators, in a consensus process involving WHO and International Disability and Development Consortium. Pilot implementations in Guatemala, Egypt and China using a specifically developed mobile phone application to collect data, and an online expert survey were completed to assess validity and feasibility of the indicators and their corresponding questions.

Results

The indicator set includes 13 Base Indicators which are broad enough to capture the situation of people with disability in settings where CBR is carried out, independently of the specific CBR activities carried out in a community; and 27 Supplementary Indicators that provide more specific coverage and can be selected based on the specific goals of a CBR program.

Conclusion

The indicators were suitable to assess differences in health, education, social life, livelihood and empowerment between people with disability and other community members. This comparability provides valuable information to CBR managers, donors and government agencies, to guide decision making, support advocacy and improve accountability. The

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CBR indicators will support WHO and its member states in their efforts towards strengthening CBR, by generating evidence on its effectiveness.

Introduction

Community-based Rehabilitation (CBR) is an umbrella-term for strategies "within general community development for rehabilitation, equalization of opportunities, and social inclusion of all people with disabilities" that aim to address their wider needs in their communities. CBR is implemented through the combined efforts of people with disability themselves, their families and communities, and the relevant service sectors[1]. CBR is implemented in over 100 countries, evolving from its initial focus on limitations and barriers experienced in low-and middle-income countries to also be relevant for higher-income countries [2,3]. However, CBR coverage is usually very low regarding the proportion of people with disability receiving support, CBR is seldom integrated into health or social security systems, and is instead usually financed and provided by non-governmental organizations (NGOs)[4]. Acknowledging the importance of CBR in tackling stigma, discrimination, barriers to equal participation, and lack of appropriate services faced by people with disability[5], the World Health Organization (WHO) set strengthening CBR, particularly through fostering the improvement of CBR monitoring and evaluation, as one objective of the recently endorsed *Global Disability Action Plan*[6].

Sound and systematic CBR monitoring and evaluation is a significant challenge faced by the CBR sector in promoting and advocating for its broader implementation. While anecdotal evidence exists on the success of CBR, internationally comparable results are still rare, and reliable and comparable data needed to monitor and evaluate CBR scarce[4,7,8]. Although the existing qualitative work delivers essential in-depth understanding of the changes CBR initiates[9], the lack of standardized measures limits the generated evidence and the comparability across settings[7,10]. A recently published systematic review reporting evidence on the effectiveness of CBR in low- and middle-income countries pointed out promising results in terms of clinical outcomes, functioning and quality of life, but could not deliver clear evidence due to the heterogeneity of interventions and quality of included studies[4]. A second review examining the methods used to collect data on CBR programs corroborates the lack of standardisation. This particular review calls for the development of a data collection method which takes the complexity and heterogeneity of CBR into consideration while keeping a high level of standardisation[7].

Indeed, several attempts have been taken towards developing standardized data collection methods for CBR, by attempting to identify reoccurring CBR domains, to suggest evaluation frameworks, and to develop specific indicators. In 1995, a joint WHO workshop looked to develop outcome indicators with the goal of providing qualitative information about the effectiveness of CBR activities, with a special effort to create indicators beyond the health component of CBR[11]. One of the first attempts to introduce the use of classification models to evaluate CBR was suggested in 2000, which used four dimensions with a defined scoring system to categorize programs[12]. A few years later, Wirz and Thomas noted that many studies have attempted to compile sets of indicators to judge the effectiveness of CBR. Based on ten included studies, they identified six activity domains and derived indicators in line with these activities[13]. One year later, a workshop developed a template that comprised of a number of guiding questions within three domains, which were then later developed into a set of

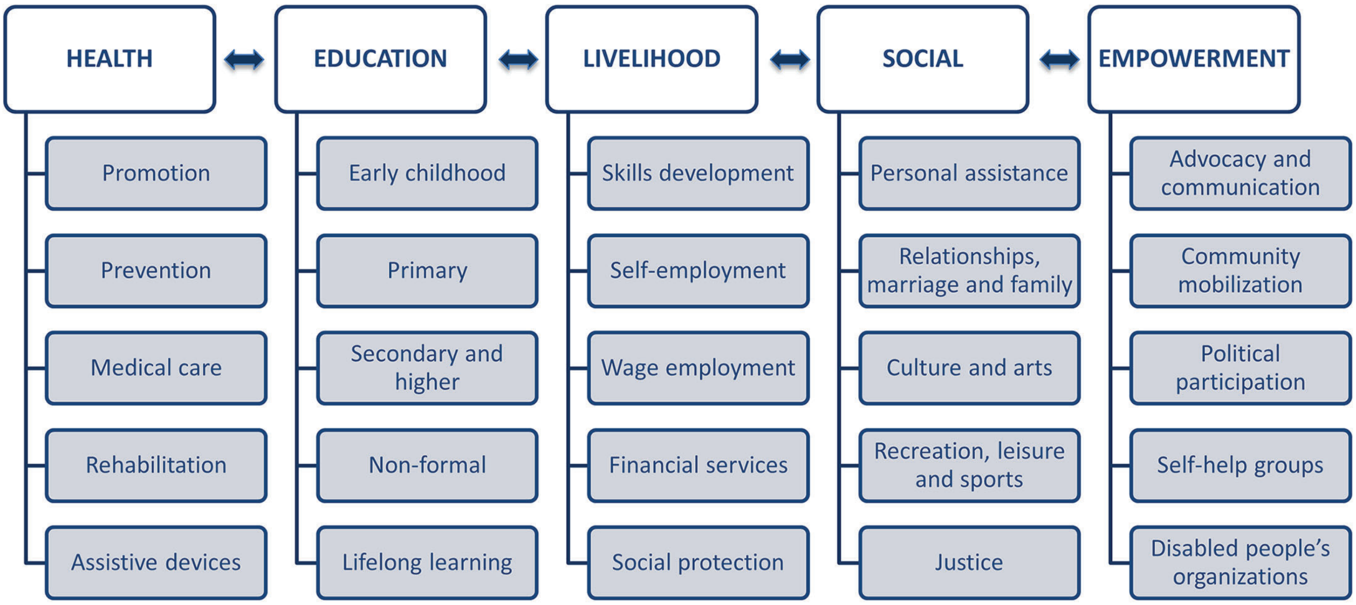

Fig 1. The CBR Matrix.

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evaluation indicators[14]. In 2010, the release of the WHO's Community-Based Rehabilitation Guidelines (hereafter CBR Guidelines) served to synthesize global perspectives on CBR, and have since become accepted internationally as a conceptual framework for CBR[15].With these guidelines, the WHO recognized that no single model of CBR is appropriate for the whole world and suggested the pre-existing CBR Matrix (Fig 1) as a common framework to reflect the comprehensive multi-sectoral strategy that is CBR. In 2012 the CBR Guidelines were used during a WHO technical meeting[16] as a guide to develop a set of indicators, focusing mainly on access to CBR services, and being in this sense restricted to a single perspective. Furthermore, consensus was not reached regarding these indicators, and they were therefore not promoted for use. A CBR Monitoring Manual and Menu, published in 2015, outlines possible methods, encourages the setup of easy and routine monitoring and provides information that can be used as building blocks for indicators. However, standardized indicators are not presented[17].

Despite these efforts towards standardization for monitoring CBR, a standardized multi-sectoral and internationally comparable set of CBR indicators suitable to monitor the changes that different CBR strategies initiate in the lives of people with disability, is lacking[4]. Previous CBR indicators, however, tend to describe practices and stakeholder perceptions, rather than asses the changes brought by these practices[13]. Furthermore, they tend to target specific CBR activities or are tailored for a specific region[14,18,19]. Indicators suitable to monitor CBR across communities and countries need to be generic in that they can be used to monitor CBR independent of the specific objectives and activities of individual CBR programs. Also absent from previous CBR indicator initiatives is the possibility of comparing people with disability and those without disability living in the same community though the use of the same indicators. Using people without disability living in the same community as a reference group is necessary in order to disclose inequalities and changes in inequalities when CBR is in place. This is of utmost importance in order to be in line with the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which states that people with disability should have equal rights as everyone else[20]. Finally, since the internationally accepted CBR Guidelines reflect the comprehensive multi-sectoral CBR strategy, indicators based on these guidelines would be the most updated way of monitoring CBR following the five components presented in the CBR Matrix: health, education, livelihood, social and empowerment[15].

Accounting for this need, WHO initiated a project to develop CBR indicators encompassing health, education, livelihood, social life, and empowerment indicators in accordance with the CBR Matrix. In the practice of CBR, input and output indicators do not provide an indication of the extent to which a program is achieving its goals or its effectiveness [21], while impacts are long-term effects that are beyond attribution to a CBR intervention as they may reflect broader societal change. Therefore, the CBR indicators were intended to be outcome indicators, as outcomes are the observable short- and intermediate-term changes in a specific group of persons in the CBR area that have been influenced by the outputs. These outcome indicators will serve to standardize monitoring of CBR across areas and countries. The adopted working definition of monitoring was: a descriptive process that provides information on the state of a programme or project at a given time, relative to its respective targets and outcomes[21]. To ensure that different perspectives in terms of CBR expertise were taken into account, and to thereby increase the uptake of the proposed indicators, the entire development was a consensus process in collaboration with the International Disability and Development Consortium (IDDC), stakeholders in the greater CBR community, as well as a team of external researchers.

The aim of this paper is to describe in detail all phases of the development process of the set of global WHO CBR outcome indicators, which were launched by WHO in December 2015. This WHO document, "Community-based rehabilitation indicators manual" (available at http://www.who.int/disabilities/cbr/cbr_indicators_manual/en/[22]), presents the indicators and the recommended data collection and reporting strategy. While the manual is meant to be a "how-to" guide for using the indicators, this manuscript presents the details of the development process for transparency.

Methods

CBR Guidelines were used as the underlying framework for developing the WHO CBR Indicators because they are internationally accepted as conceptual framework for CBR, were developed together by WHO, IDDC, the United Nations Educational, Scientific and Cultural Organization (UNESCO) and the International Labour Organization (ILO) and are based on a worldwide participatory approach with the involvement of all relevant stakeholders[15]. The CBR Guidelines synthesize global perspectives on CBR and offer recommendations on strengthening the capacity of mainstream and specific services to include people with disability in accessing the benefits of the health, education, livelihood and social sectors and enhance empowerment. For each of these five components of the CBR Matrix (Fig 1), there are five corresponding elements for which the CBR Guidelines present a set of "desirable outcomes" outlining the goals of CBR. Additionally, general overarching desirable outcomes are presented for each component. These desirable outcomes were used as a starting framework for the WHO CBR Indicators. The development process comprised four phases with specific objectives as follows.

Phase I: Preparatory work

Indicators following the CBR Guidelines' Matrix have been proposed for monitoring CBR in the past[16]. In addition, different closed and ongoing projects have proposed indicators for disability and health that might match the desirable outcomes proposed in the CBR Guidelines and are in line with the CRPD. To make sure these indicators were taken into account in the present work, previous efforts were systematically scrutinized in Phase I. The specific **objectives of Phase I** were to obtain an overview of the work previously done with the CBR Guidelines as starting point; to obtain an overview of available indicators for disability from other projects; and to study the extent to which these indicators are in line with the CRPD.

To achieve these goals an extensive internet search was used to identify disability and population health indicators from initiatives around the world. Indicators from the following projects were included: Human Development Index (http://hdr.undp.org/en/humandev); Millennium Development Goals (http://www.unmillenniumproject.org/goals/); WHO Model Disability Survey (MDS—these indicators were derived directly from the questions, specifically for this study) (http://www.who.int/disabilities/data/mds/en/); UNICEF Multiple Indicator Cluster Survey 4 (UNICEF MICS4) (http://www.unicef.org/statistics/index_24302.html); WHO Global Disability Action Plan; (http://www.who.int/disabilities/actionplan/en/); WHO Core Health Indicators; (http://www.who.int/healthinfo/indicators/2015/en/); and the Zero Project (http://zeroproject.org/indicators-2/). All identified disability and health indicators, as well as the desirable outcomes of the CBR Guidelines were mapped to the CRPD (articles 5 to 30) by two researchers (SA, CM) in order to facilitate comparison.

Phase II: Framework development

The objective of Phase II was to use the desirable outcomes published in the CBR Guidelines as a starting point for developing CBR indicators. Although labelled as "desirable outcomes", several are formulated rather as output or even impact indicators. In addition, several are dependent on specific CBR objectives, not sensitive to changes at the person level, or not suitable for comparisons across regions. **To achieve this objective** the following three steps were taken:

1. Revising the desirable outcomes to provide a consistent underlying framework for formulating CBR indicators. The revision was a consensus process. Five researchers (hereafter CBR Group) independently categorized each desirable outcome as an input, output, outcome, or impact in accordance with OECD definitions[21]. Modal frequency response analysis was conducted, and where the modal response was not "outcome", the desirable outcomes were re-formed. This reformation involved a content analysis of the original desirable outcome to formulate it as a true outcome result, expressed at the person level (i.e. "People with disability and their families in the CBR area. . ..") using an active voice. The individually re-formed desirable outcomes were compiled and the most adequate was selected through an anonymous majority-rule vote. For example the desirable outcome for Health-Assistive Devices originally states: "*Environmental factors are addressed to enable individuals to use their assistive devices in all locations where they are needed*". The CBR Group unanimously categorized this as an output and voted to reformulate it as "*People with disability use their assistive devices in all areas of the community they need to*"
2. Excluding desirable outcomes that could not be revised to be suitable for cross-sectional and international comparisons using the criteria above. For example, the Empowerment-Political Participation desirable outcome which states "*CBR personnel have increased awareness of the political system*"
3. Selecting the most adequate remaining desirable outcome in terms of feasibility and reliance of information delivered, per component and element of the CBR Matrix. In a two-day workshop the original and re-formed desirable outcomes were presented to IDDC

members with CBR expertise. Participants were randomly assigned into two working groups of six persons each. The task was to select or develop one desirable outcome per general component level and one per element of the Matrix, by analysing the content of the desirable outcomes, drawing on field experiences and finally coming to a consensus in the working group. After completing the working groups' tasks, plenary sessions with all participants took place presenting the original desirable outcomes, CBR Group suggestions, and working groups' suggestions. The consensus process involved collaborative decision-making with super majority threshold of 75% agreement. This led to the selection of the most adequate desirable outcomes, in terms of coverage of the concepts presented per component and element. For example for Social-Component Level, five desirable outcomes are presented. Two were excluded. Of the remaining three—"*People with disability are valued as members of their families and have a variety of social roles and responsibilities*", "*People with disability are encouraged and supported to contribute their skills and resources to the development of their communities*", "*Communities recognize that people with disability are valued members, and can make positive contributions to the community*"—the most adequate single formulation was voted to be: "*People with disability feel valued as community members and have a variety of social identities, roles and responsibilities*". When the majority threshold was not reached in the face-to-face meeting, the CBR Group created suggestions which were circulated and edited via email until the majority threshold was met.

Phase III: Alpha-version of CBR indicators

Phase III had the objective of developing an alpha-version of CBR indicators and corresponding questions, along with a sound and simple method for data collection in low resource settings. **To achieve this**, the selected desirable outcomes of Phase II were formulated as proportion indicators at the person level, comparing people with disability to other community members of the same age and gender. To collect data from the indicators, the next step involved developing a survey question for each indicator. Indicators were operationalized into a question or a response option of an overarching question. The use of standardized questions from validated questionnaires or surveys was preferred. When no such standardized question was available, new questions were developed. Questions were proposed by the CBR Group and reviewed by IDDC members in consensus until the majority threshold was reached. Question validation was conducted through pilot implementations. These questions are, however, a suggestion and independent of the indicators: users of the CBR indicators are free to use their own questions to operationalize the indicators. A mobile phone application (app) for android phones was developed to provide an easy-to-use method for data collection (see [22], and https://www.youtube.com/watch?v=NEfJYoGX3uU&t=3s). An interviewer's manual was prepared for Phase IV (available in [22]).

Phase IV: Feasibility and validity testing

Phase IV involved the final selection of the set of WHO CBR Indicators and testing the feasibility and acceptability of using a mobile phone app for data collection. In order to make data collection as brief as possible, the set of indicators was broken down into two subsets: base indicators which are broad and should be used in all data collection activities to ensure comparability, and supplementary indicators which can provide more specific coverage of the CBR elements and can be selected depending on the specific CBR goals of a program. **This**

was achieved through data collection in pilot implementations and an online expert survey in order to determine the relevance of indicators and face validity of questions.

The pilot implementations were carried out in three countries representing three world regions: Guatemala, Egypt and China. Pilots included both persons participating in CBR selected by CBR project managers, and a comparable number of community members without disability matched for age, gender and area of residence for comparison. Interviewers were local CBR staff members, trained by members of the CBR Group in a two day workshop. Since a comparison between boys, girls, men and women was targeted, a gender-balanced convenience sample was recruited and no age restriction was applied. To obtain an overview of unsuitable questions, the distributions of questions' response options were examined: high proportions of "don't know" responses were indicative of an underlying problem, and these questions were highlighted as candidates for elimination. To further examine the feasibility and acceptability of the questions, interviewers reported questions they found problematic, for reasons such as the question was confusing, complicated, embarrassing or required follow-up. Questions being marked as problematic in more than 10% of interviews were examined for problems and revised accordingly, while questions with more than 20% were considered for elimination. Additionally, interviewers in Guatemala, the first country running the pilot implementations, participated in focus groups targeting problems regarding conducting interviews and using the app.

The expert survey was internet-based and aimed to gather information on relevance of indicators and validity of questions. Experts working in the field or in CBR research from all six WHO world regions and from varying occupational backgrounds were invited to participate. These experts were all recommended by IDDC. The survey consisted of two parts. After being presented the background of this project, experts were first requested to rank the given list of developed indicators per element of the CBR Matrix in terms of relevance to that element. Second, experts were requested to rate on a scale from 1 (completely adequate) to 5 (not at all adequate), the adequacy of each question as to whether it would retrieve the required information for the indicator. If a question was rated as inadequate, experts were requested to provide feedback and an alternative question.

Results and feedback of the pilot implementations and the expert survey were reviewed by the CBR Group and IDDC, allowing for the selection of a final set of CBR indicators and questions.

Results

Phase I: Preparatory work

Of the seven initiatives examined, the WHO Model Disability Survey, WHO Disability Action Plan, and Zero Project present disability-specific indicators. The other projects present general indicators. The most comprehensive coverage of the CRPD and the wide scope of CBR was provided by the MDS (n = 19), UNICEF MICS4 (n = 13), HDI (n = 12), Zero Project (n = 9), MDGs (n = 7), WHO Disability Action Plan (n = 6), and WHO Core Health Indicators (n = 5) (Table 1). The desirable outcomes of the CBR Guidelines covered 23 out of 26 selected CRPD articles.

Phase II: Revision of CBR desirable outcomes

Forty-eight of the 174 original desirable outcomes were eliminated for being dependent on specific objectives and activities of CBR, or for not being sensitive to changes at the person level in settings where CBR is carried out. In the components of education and livelihood it was found that some concepts reoccurred throughout the elements. In these cases, the cross-

Table 1. Number of indicators from each project which were linked to the CRPD articles.

CRDP Article		CBR desirable outcomes	HDI	MDGs	MDS	UNICEF MICS4	WHO Core Health	WHO Disability Action Plan	Zero Project
5	Equality and non-discrimination	1			2				
6	Women and disabilities	3	5	3	1	4			
7	Children with disabilities		1	4	2	1			
8	Awareness-raising	11			25				
9	Accessibility	10			22	3		1	12
10	Right to life	1				6	5		
11	Situations of risk and humanitarian emergencies	1							1
12	Equal recognition before the law	6			3				1
13	Access to justice	4	1						1
14	Liberty and security of the person	1	3						
15	Freedom from torture or cruel, inhuman or degrading treatment or punishment	1				3			
16	Freedom from exploitation, violence and abuse	1	2			6			
17	Protecting the integrity of the person	3				1			
18	Liberty of movement and nationality		2		6		1		
19	Living independently and being included in the community	29		5	16			2	4
20	Personal mobility	8			9	3		1	
21	Freedom of expression and opinion, and access to information	8			4	3			6
22	Respect for privacy				2				
23	Respect for home and the family	4	2	6	20	22	6		1
24	Education	33	14	5	20	19			3
25	Health	16	5		66	45	38	9	
26	Habilitation and rehabilitation	15			43			8	
27	Work and employment	18	6	2	28				9
28	Adequate standard of living and social protection	7	6	6	18	13	10	1	
29	Participation in political and public life	7	1		3				
30	Participation in cultural life, recreating, leisure and sport	12			6				
NUMBER OF ARITCLES COVERED		**23**	**12**	**7**	**19**	**13**	**5**	**6**	**9**

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cutting concepts were formulated into single desirable outcomes which were moved to the general component level. For example, in the education component the concept of "*Children, youth and adults with disability experiencing equal opportunities to participate in learning opportunities that meet their needs*" reoccurs in all the elements of education, namely early childhood education, primary, secondary, non-formal education and lifelong learning. For this reason this concept was moved to the general component level. As a consequence, primary, secondary and non-formal education no longer had individual desirable outcomes. In livelihood, the concept of "*People with disability earning income through their own chosen economic activities*" reoccurs in the elements of self-employment and wage employment. These were moved to the general component level so that these elements no longer had individual desirable outcomes. Also within livelihood, the element of skills development had overlap with the lifelong learning component of education. For this reason it was decided to incorporate it into lifelong learning.

The set agreed on at the end of the consensus process with IDDC consisted of 41 re-formed desirable outcomes (Fig 2).

Phase III: Alpha set of CBR indicators

Most of the 41 re-formed desirable outcomes (n = 23) were formulated as single indicators; for example "*Men, women, boys and girls with disability feel they are respected and treated with dignity when receiving health services*" into "*% of people with disability who rate their experience of being treated with respect and dignity by health service providers as good or very good*". Nine desirable outcomes contained information that was formulated into two indicators; for example "*Men and women with disability access formal and informal social protection measures they need*" into "*% of people with disability who know how to access social protection measures*" and "*% of people with disability who are covered by social protection programs*". Similarly, two desirable outcomes were formulated into three indicators. Ten desirable outcomes were combined pairwise into single indicators; for example "*Men, women, boys and girls with disability make use of youth or adult centered learning opportunities to improve their life skills and living conditions*" and "*Men, women, boys and girls with disability experience equal opportunities to participate in learning opportunities that meet their needs and respect their rights*" were formulated into "*% of people with disability who use life-long learning opportunities to improve their life skills*". Full formulations are presented in S1 Appendix. It was agreed that differences experienced by men, women, boys and girls would be examined through stratification in the data analysis, and not directly addressed in the formulation of each indicator. A set of 52 alpha-version indicators were operationalized from the 41 re-formed desirable outcomes.

In total, 40 indicators were operationalized into single and four into multiple questions. Eight indicators were operationalized as response option for two overarching questions. At this stage, 51 alpha-version questions were proposed: six originally from and eight adapted from the MDS, three adapted from the UNICEF MICS3, one adapted from the GALLUP Annual Consumption Habits Poll[23], and one from the WHO Quality of Life-BREF[24]. The remaining 32 questions were developed by the CBR Group and reviewed by IDDC members in a consensus process (see S1 Appendix). This alpha-version contained 52 indicators and 51 corresponding questions that were then implemented in the app.

Phase IV: Feasibility and validity testing

The total sample of the pilot implementations consisted of 801 participants, 53.4% female, with a mean age of 29.6 (SD 21.3). Further characteristics of participants are reported in Table 2.

Nineteen questions (37.3%) were reported as problematic in more than 10% of interviews, with five questions (9.8%) reported as problematic in more than 20% of interviews. Main problems reported by interviewers were that the question was confusing or difficult to understand, or that the question needed follow-up or clarification. Most problems were reported in Egypt (70.3%), followed by Guatemala (27.5%), and then China (2.2%). Focus groups in Guatemala, the first country carrying out the implementation, revealed problems that were then addressed before the pilots in Egypt and China. An overarching problem was the high complexity of some questions, and difficulties with the response options, which ranged from 5(completely) to 1(not at all). For this reason, response options were re-ordered from 1(not at all) to 5 (completely), and show cards were used for visual representations in Egypt and China.

The expert survey invited 72 experts to participate, with 31 completing the survey. The majority of participants were male (54.8%) and worked in NGOs or INGOs (61.3%), while those who had worked in the field of CBR for 20 years or more (35.5%) and those working in

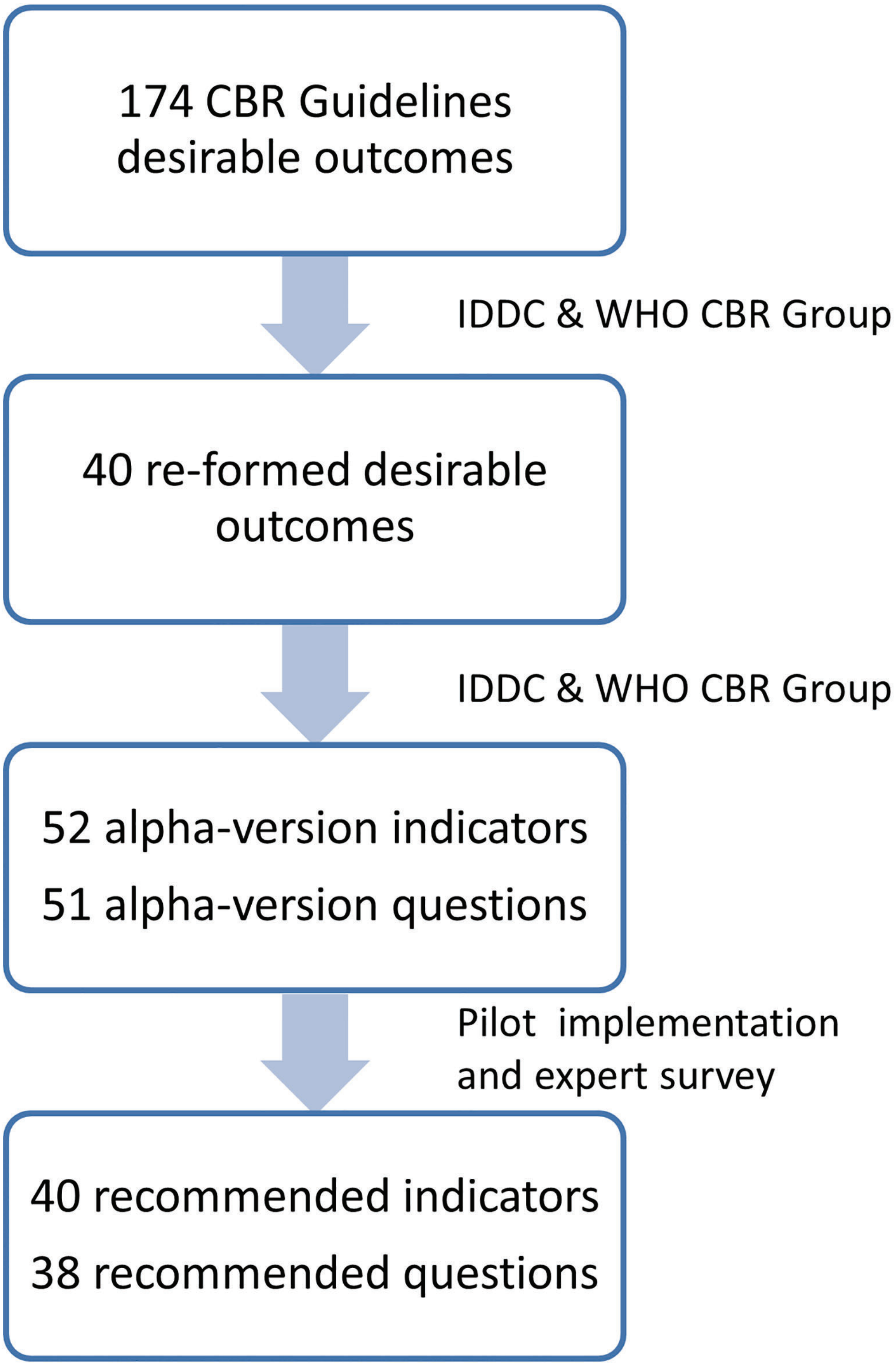

Fig 2. The process beginning with the CBR Guidelines desirable outcomes and leading to the WHO recommended CBR indicators.

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Table 2. Descriptive statistics of the 801 pilot implementation participants.

	China N (%)		Egypt N (%)		Guatemala N (%)		Total N (%)	
	Control (n = 132)	People with disability (n = 128)	Control (n = 118)	People with disability (n = 119)	Control (n = 160)	People with disability (n = 143)	Control (n = 406)	People with disability (n = 395)
Gender (female)	74 (57.8)	70 (53.0)	65 (55.1)	55 (46.2)	102 (63.8)	62 (43.4)	241 (59.4)	187 (47.5)
Proxys used	0	5 (3.8)	38 (32.2)	59 (49.6)	77 (49.0)	109 (76.8)	115 (28.6)	173 (44.1)
Children	5 (3.9)	13 (9.9)	36 (30.5)	43 (36.4)	76 (48.4)	93 (66.0)	143 (35.2)	163 (41.4)
Mean age (SD)	42.1 (±19.0)	46.0 (±20.4)	31.1 (±20.4)	31.2 (±21.4)	17.4 (±11.9)	13.6 (±10.9)	29.5 (±20.2)	29.8 (±22.4)

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the South-East Asia Region (38.7%) represented the largest proportions of respondents (Table 3). Per component and element, the indicator ranked as the most relevant by the majority of experts was selected. In cases where no indicator reached a majority vote, the top indicators were examined and selected by the CBR Group.

The analysis of the results of the survey and the pilot implementations led to the selection 40 CBR indicators[22]. The indicators are broken down into two sets: 13 base and 27 supplementary indicators. Base indicators are broad enough to capture the situation of people with disability, independent of specific CBR activities carried out and are derived from the general component level desirable outcomes. These indicators are recommended to be included in any data collection. All but one of the component level desirable outcomes was selected as a base indicator. The exception was the general livelihood indicator of "*People with disability get to make their own decisions about how to use their money*". The CBR Group saw that the concept of "*People with disability having enough money to meet their needs*" was not covered by any indicator, and therefore created this as a base indicator, with the initial indicator remaining as

Table 3. Demographic characteristics of the 31 expert survey participants.

		N (%)
Gender	Female	14 (45.2%)
Age	under 40	8 (25.8%)
	40–59	15 (48.4%)
	60+	8 (25.8%)
Time period spent working in the field of CBR	Under 10 years	13 (41.9%)
	10–19 years	7 (22.6%)
	20+ years	11 (35.5%)
Primary world region of work	African Region	5 (16.1%)
	Region of the Americas	2 (6.5%)
	South-East Asia Region	12 (38.7%)
	European Region	1 (3.2%)
	Eastern Mediterranean Region	3 (9.7%)
	Western Pacific Region	5 (16.1%)
	Global	3 (9.7%)
Primary working position	Academia	11 (35.5%)
	DPO	1 (3.2%)
	NGO/INGO	19 (61.3%)
	Government	2 (6.5%)
	Other	6 (19.4%)

https://doi.org/10.1371/journal.pone.0178418.t003 a supplementary indicator. Supplementary indicators provide more specific coverage of the CBR elements and can be selected depending on the specific goals and strategies of a program. Base CBR indicators have eight corresponding questions and supplementary have 30 corresponding questions. The WHO manual presents the full set of indicators and the data collection procedures[22].

Discussion

The aim of this paper was to describe in detail all phases of the development process of a recently launched set of global CBR outcome indicators, based on the CBR Guidelines, which are suitable to monitor CBR. The proposed set of indicators includes 13 base and 27 supplementary CBR indicators, is grounded on the internationally acknowledged CBR Guidelines, and is the result of a collaborative, consensus-orientated and evidence-based effort between WHO, IDDC and the broader CBR community. These indicators will serve to capture the situation of people with disability in settings where CBR is carried out, independent of the specific objectives and implemented activities of a program. These indicators will support WHO and member states in their efforts towards strengthening CBR, as requested in the *Global Disability Action Plan*, through generating evidence on the effectiveness of CBR [6]. The use of the proposed CBR indicators will generate the evidence needed by NGO's, DPO's, and the broad community involved in CBR to advocate for broader and integrated CBR implementation in different settings, including at the national level.

The use of the CBR Guidelines as a multi-sectorial reference framework for the CBR indicators is essential. Due to the heterogeneity and varying contexts in which CBR is implemented, an appropriate framework is needed as a basis for the monitoring process [4,7]. The CBR Guidelines and the corresponding desirable outcomes were selected as a framework for the proposed CBR indicators as they encompass a unified understanding of CBR concepts in line with the CRPD[9,25]. Though a global set was previously suggested[13,26], there is some disagreement as to whether a global set of indicators, even when based on the CBR Guidelines and the corresponding matrix, can cover the cultural and methodological diversity of CBR[18,19]. To account for this, the CBR indicators proposed here take advantage of the several elements of each CBR Matrix component and use them to offer a possibility of customizing data collection. Stakeholders responsible for data collection are requested to use the 13 base CBR indicators in all data collection to guarantee standardisation and comparability. However, additional indicators can be selected out of the 27 supplementary CBR indicators so that the data collection can be shaped to monitor more specific programs' goals, cultural settings, or requirements of funding bodies. In summary, the indicators presented in this project combine the advantage of providing a means of collecting global data for cross-program comparisons, while also addressing the diversity of CBR by allowing the flexibility to customize data collection.

The flexibility presented in indicator selection and the corresponding mobile phone app help to encourage the uptake of the CBR indicators by making data collection as quick and simple as possible. Providing intuitive procedures to customize and carry out data collection allows data collection to be carried out by any community member, which is in line with suggestions that the monitoring process should involve community members and people with disability to allow for engagement of the local community, thereby fostering greater community ownership and sustainability[9]. The app is free to download on Google Play and works offline. Interviews using base indicators can be completed within five minutes. Interviews are either submitted to a selected e-mail address or anonymously to a central and secure server located at WHO upon acceptance of the data protection agreement on the phone.

Furthermore, in order to increase the motivation for data collection, if completed interviews are submitted to the central server, the data will be organized so that the indicator results can be presented as diagrams. These diagrams will be able to show the differences between people with disability and those without disability in the community surveyed, and within those groups, the differences between boys, girls, men and women. In case stakeholders are willing to share the data with WHO and the CBR community, anonymous comparisons of different programs and regions will be implemented in the CBR page of WHO's website.

The CBR indicators proposed at present are the first necessary step towards the global monitoring and evaluation of CBR. They focus on monitoring and on outcomes at the individual level with the results from each indicator allowing for the identification of discrepancies experienced by people with disability. For example, when the indicator *"% of people with disability who acquire education in mainstream education facilities"* presents low percentage it can indicate exclusion of people with disability from their peers. These results can be further interpreted to see the effects on the community members as a whole. The next step in the monitoring process of CBR is to broaden the perspective by developing system indicators suitable to capture societal, administrative, attitudinal, and environment changes. Further work is also needed to develop sound and reliable indicators for the evaluation of CBR, in terms of creating making systematic judgements regarding the relevance, fulfilment of objectives, efficiency, effectiveness, impact, and sustainability of CBR[21]. As CBR is a continuous process there is an urgent need for longitudinal data to capture change over time, both for monitoring and evaluation, which will come through follow-up data collection.

Some limitations that come as an inherent result of using indicators, as is the case for the CBR indicators, should be mentioned here. People may argue that indicators have been shown to lead to over-aggregation and over simplification of data while only measuring what is quantifiable, and not always match to what is important to people[27]. Being unaware of this can lead to overconfidence in the relevance of the data collected, and thereby lead to incompleteness in the overview the indicators should generate. Furthermore, data gathered with indicators should be complemented with data from direct experience if an in-depth understanding is targeted, which can only be collected through qualitative approaches[27]. These facts might result in reluctance to use the CBR indicators. It is important to stress, however, that until now qualitative studies have dominated the field of CBR, and that despite all research carried out, recent reviews continue to stress the lack of evidence on the effectiveness of CBR [4]. In this sense, the proposed indicators may suffer from the inherent shortcomings of indicators, but they provide a unique opportunity to collect standardized global data on CBR after more than 30 years of attempts to do so. Data collected with the indicators, combined with results from available qualitative work, could finally prove what is strongly assumed, namely that CBR is effective and worth the effort required for implementation.

Finally, it is important to stress that the *Global Disability Action Plan* explicitly calls for the strengthening of CBR through monitoring and evaluation[6]. It is strongly recommend that qualitative work on disclosing potential sector, country, regional or cultural barriers, as usually done in implementation research, be carried out alongside the first implementations of the CBR indicators. Researchers and stakeholders are encouraged learn from data collection efforts and to contribute to the further development of strategies that can guarantee uptake of the CBR indicators. Users of the CBR indicators proposed here are therefore called to be active participants in achieving this goal by periodically collecting data, by reporting their experiences during data collection and by sharing data with WHO and the CBR community. This will contribute to the creation of a strong evidence base that can ultimately deliver arguments to improve CBR and potentially advocate for broader and more sustainable implementation.

Conclusion

The use of the CBR indicators proposed in this work and corresponding questions allow for reliable, easy and comparable data collection to demonstrate the effect of CBR, and thereby potentially broaden the appeal for its implementation. These indicators capture the situation of people with disability in comparison to other community members in the aspects of health, education, social life, livelihood and empowerment, as outlined in the CBR Guidelines[15]. When data is collected over time in a community it will capture changes in the lives of people with disability, as well as support monitoring of the implementation of the CRPD at the community level in an easy and efficient way. These indicators allow for further comparability across settings and countries. The CBR indicators are understood as a starting point towards generating sound and standardised evidence for CBR. Further work is needed to complement these indicators with system level indicators tackling factors in the environment, to identify barriers that might prevent their uptake, and to develop methods of using the generated information in economic evaluations of CBR.

Supporting information

S1 Appendix. Revised desirable outcomes and the corresponding alpha-version of indicators and questions resulting from the IDDC consultation.
(DOCX)

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Appendix 1: Revised desirable outcomes and the corresponding alpha-version of indicators and questions resulting from the IDDC consultation

HEALTH COMPONENT

CBR Guidelines Element	Revised Desirable Outcome	Indicator	Question
General	Men, women, boys and girls with disability equally access health services and engage in activities needed to achieve the highest attainable standard of health	% of people with disability who rate their health as good or very good	I will start with a question about your overall health, including your physical and your mental health: 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	Men, women, boys and girls with disability feel they are respected and treated with dignity when receiving health services	% of people with disability who rate their experience of being treated with respect and dignity by health service providers as good or very good	On your last visit to a health care provider, to what extent are you satisfied with the level of respect you were treated with? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Promotion	Men, women, boys and girls with disability know how to achieve good levels of health and participate in activities contributing to their health	% of people with disability and their families that know (aware of) that physical activity and eating habits influence their health	Has your (doctor, CBR worker, or any other health professional) ever discussed with you the benefits of eating a healthy diet, engaging in regular physical exercise, or not smoking? 1=Yes; 2=No
Prevention	Men, women, boys and girls with disability participate in activities that prevent them and future generations from getting ill	% of people with disability who receive full immunization as recommended for their country by WHO	When was the last time you have been vaccinated? 1 = In the last 5 years; 2 = In the last 5-10 years; 3 = Longer than 10 years; 4 = Never
Prevention		% of children with disability who receive full immunization as recommended for their country by WHO	When was the last time [NAME] was vaccinated? 1 = In the last 2 years; 2 = More than 2 years; 3 = Never
Prevention		% of children with disability who receive the recommended health check-ups	When was the last time [NAME] had a health check-up? 1 = In the last year; 2 = Between 1-2 years ago; 3 = Between 3-5 years ago; 4 = Longer than 5 years ago; 5 = Never
Prevention	Decision makers and community actively engage in reducing health conditions	% of people with disability who live in communities where decision makers actively engage in reducing health conditions	To what extent have people in your community done anything to make your neighbourhood a cleaner, healthier, and safer place to live? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Medical Care	Men, women, boys and girls with disability access and benefit from quality medical services appropriate to their life stage needs and priorities	% of people with disability that needed medical care in the last 12 months and did not get the care they need	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

Medical Care		% of people with disability and their families that have access to medical care	Which reason(s) best explain why you did not get health care? 1=Health care facility too far away; 2=Could not afford the cost of the visit; 3=No transport available; 4=Transport not accessible; 5=Could not afford the cost of transport; 6=Were previously badly treated; 7=Could not take time off work or had other commitments; 8=Health care provider's drugs or equipment were inadequate; 9=Health care provider's skills were inadequate; 10=Did not know where to go; 11=Tried but were denied health care; 12=Thought you were not sick enough; 13=Other
Medical Care		% of people with disability that have the experience of being involved in making decisions for their treatment	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

HEALTH COMPONENT - Continued

CBR Guidelines Element	Revised Desirable Outcome	Indicator	Question
Rehabilitation	Men, women, boys and girls with disability engage in planning and carry out rehabilitation activities with the required services	% of people with disability that needed rehabilitation services in the last 12 months and did not get the services they need	In the last 12 months, has there been a time when you needed rehabilitation services, such as physical, occupational, or speech therapy, but did not get those services? 1=Yes; 2=No
Rehabilitation		% of people with disability that have access to rehabilitation services	Which reason(s) best explains 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	Men, women, boys and girls with disability have access to, use, and know how to maintain appropriate assistive products in their daily life	% of people with disability that have access to assistive products appropriate to their needs	Do you use any aids to help you get around such as cane, crutch, or wheelchair; or to help you with self-care such as grasping bars, hand, or arm brace? 1=Yes, and it works well; 2=Yes, but it doesn't work or isn't appropriate; 3=No, but I need it; 4=No, because it's broken or not appropriate; 5=No, I don't need it

Assistive Devices			Do you use anything to help you to see better, such as glasses? 1=Yes, and it works well; 2=Yes, but it doesn't work or isn't appropriate; 3=No, but I need it; 4=No, because it's broken or not appropriate; 5=No, I don't need it
Assistive Devices			Do you use anything to help you hear or communicate better? 1=Yes, and it works well; 2=Yes, but it doesn't work or isn't appropriate; 3=No, but I need it; 4=No, because it's broken or not appropriate; 5=No, I don't need it
Assistive Devices		% of people with disability using assistive devices that know how to maintain them	Do you know how to keep your assistive device in good working condition? 1=Yes; 2=No

EDUCATION COMPONENT

CBR Guidelines Element	Revised Desirable Outcome	Indicator	Question
General	Policies and resources are conducive to education for people with disability and ensure smooth transitions through different stages of learning Children with disability participate in and complete quality primary education in an enabling and supportive environment Men, women, boys and girls with disability have resources and support to enroll and complete quality secondary and higher education in an enabling and supportive environment Youth with disability experience post school options on an equal basis with their peers	% of youth with disability that have completed secondary education before age 20 % of youth with disability who are attending secondary education % of people with disability who are attending or have completed higher education % of people with disability who have educational or vocational options after obtaining their educational certificate or degree % of people with disability who have professional training	What is the highest level of education that you have achieved? If currently receiving education: What is the grade that you are currently working towards completing? 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
General		% of people with disability who acquire education in mainstream education facilities	Where did/do you receive your education? 1=Regular institutions; 2=Specialized institutions; 3=Home-schooling; 4=Other forms of education

General	Children and youth with disability participate in a variety of non-formal learning opportunities based on their needs and desires	% of people with disability who participate in learning opportunities that meet their needs	To what extent does your education contribute to achieving your goals? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
General		% of people with disability study in enabling and supportive environment	To what extent were/are you included and accepted by your teachers and peers? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Early Childhood	Children with disability actively participate in early childhood developmental activities and play, either in a formal or informal environment	% of children with disability age 36-59 months who are participating in early childhood education activities	Does [NAME] attend any organized learning or early childhood education programme, such as a private or government facility, including kindergarten or community child care? 1=Yes; 2=No
Lifelong Learning	Men, women, boys and girls with disability make use of youth or adult centered learning opportunities to improve their life skills and living conditions	% of people with disability who use life-long learning opportunities to improve their life skills	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 COMPONENT			
CBR Guidelines Element	**Revised Desirable Outcome**	**Indicator**	**Question**
General	Men and women with disability have paid and decent work in the formal and informal sector on equal bases with others Women and men with disability earn income through their own chosen economic activities Youth and adults with disability acquire marketable skills on an equal basis with others through a range of inclusive training opportunities	% of people with disability who are self-employed or own-account workers % of people with disability who are working for wages or salary with an employer	What is your current working situation? 1=Not working and looking for work; 2=Not working and not looking for work (for example student or housewife.); 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 three 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 due to age; 9=Early retirement; 10=Other

General	Inclusive policies, practices and appropriate resources, defined with PwD, enable equal participation of women and men with disability in livelihood (training, finance, work opportunities and social protection)	% of people with disability who are involved in developing inclusive policies and practices for equal participation in the labour sector	Do you engage in local or national organizations working towards disability inclusive working conditions? 1=Yes; 2=No
General	Women and men have control over the money they earn	% of people with disability who get to make decisions of how to use his/her money	Do you get to decide how to use your money? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Financial Services	Men and women with disability have access to grants, loans and other financial services on an equal basis with others	% of people with disability who know how to access financial services	Should you need financial services such as credit, insurance, grants, savings programs, would you know how to get them? 1=Yes; 2=No
Financial Services	Men and women with disability participate in local saving and credit schemes	% of people with disability who use financial services such as grants and loans	Do you currently have any credit, insurance, grants, or savings programs related to your work? 1=Yes; 2=No
Social Protection	Men and women with disability access formal and informal social protection measures they need	% of people with disability who know how to access social protection measures	Should you need social protection against loss of income through old age, sickness or disability, would you know how to receive it? 1=Yes; 2=No
Social Protection		% of people with disability who are covered by social protection programs	Do you currently benefit from any social protection program? 1=Yes; 2=No

SOCIAL COMPONENT			
CBR Guidelines Element	Revised Desirable Outcome	Indicator	Question
General	Men, women, boys and girls with disability feel valued as community members and have a variety of social identities, roles and responsibilities	% of people with disability that feel valued as individuals by members of their community	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
General	Men, women, boys and girls with disability feel safe in their family and community	% of people with disability who feel safe in their family and community	Do you feel safe in your everyday life? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Personal Assistance	Men, women, boys and girls with disability access and control the way needed personal assistance is provided	% of people with disability who get to make their own decisions about the personal assistance they need	Do you get to make decisions about the personal assistance that you need (who assists you, what type of assistance, when to get assistance)? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely

Relationships, Marriage, and Family	Men, women, boys and girls with disability experience support of the community and their families to socialize and form age-appropriate and respectful relationships	% of people with disability who get to make their own decisions about their personal relationships	Do you get to make your own decisions about your personal relationships, including family, friends and coworkers? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Relationships, Marriage, and Family		% of people with disability who feel respected in their decisions regarding personal relationships	And to what extent do you feel the people around you respect these decisions? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Culture and Arts	Men, women, boys and girls with disability participate in artistic, cultural or religious events in and outside their home as they choose	% of people with disability who get to participate in artistic, cultural or religious activities	Do you get to participate in artistic, cultural or religious activities? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Recreation, Leisure, and Sports	Men, women, boys and girls with disability participate in inclusive or specific recreation, leisure and sports activities	% of people with disability who get to participate in mainstream recreational, leisure and sports activities	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
Recreation, Leisure, and Sports		% of people with disability who get to participate in recreational, leisure and sports activities for people with special needs	To what extent are the recreational, leisure and sports activities adapted to suit your needs? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Justice	All PwD are recognized as equal citizens with legal capacity	% of people with disability who know their legal rights	To what extent do you know your legal rights? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Justice	PwD access and use formal and informal mechanisms of justice	% of people with disability who know how to access mechanisms of justice	Should you need to access the justice system, would you know how to? 1=Yes; 2=No
Justice		% of people with disability who use mechanisms of justice	Do you currently make use of formal or informal forms of justice? 1=Yes; 2=No
Justice		% of people with disability that are satisfied with the level of respect and dignity that they receive from the stakeholders in the justice sector	To what extent are you satisfied with the level of respect you are treated with by people working in the formal and informal justice system, such as police officers, lawyers, judges, or any other justice authority in the community? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely

EMPOWERMENT COMPONENT			
CBR Guidelines Element	Revised Desirable Outcome	Indicator	Question

General	PwD make informed choices and decisions	% of people with disability who get to make informed choices and decisions	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	PwD advocate for and or exercise their rights	% of people with disability who know and exercise their rights	Do you think that the laws and policies in your country provide people with disability equal rights as other people? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
General			Should your rights (such as accessing education or voting) be denied or violated would you know what to do? 1=Yes; 2=No
Advocacy and Communication	Men, women, boys and girls with disability effectively use communication skills and resources (including supportive decision making) to facilitate interactions and influence change	% of people with disability who have the communication skills to express their wishes and objections effectively	Are you satisfied with your ability to communicate with other people? For example, how you say things or get your point across 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Community Mobilization	Men, women, boys and girls with disability play a catalyzing role in mobilizing key community stakeholders to create an enabling environment	% of people with disability who have a role in shaping their communities to achieve equal opportunities for all	Do you get to influence the way your community responds to the needs and rights of people with disability? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely
Political Participation	Men and women with disability participate in political processes on an equal basis with others	% of people with disability who engage in local or national politics and in civil society organizations	Did you vote in the last election? 1=Yes; 2=No
Self-Help Groups	PwD actively engage in and benefit from self-help groups in the local communities, if they choose (inclusive or specific)	% of people with disability who actively engage in and benefit from 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
Self-Help Groups	Self-help groups come together to form federations to harness collective energy and influence positive change	% of people with disability who are members of self-help groups which are part of a larger federation	Is your self-help group a member of a federation of self-help groups? 1=Yes; 2=No
Disabled People's Organizations	Men and women with different kinds of disability living in different situations (rural or urban areas, poor or rich, refugees) feel they are adequately represented by DPO DPOs are influential stakeholders in decision-making	% of people with disability who feel that they are adequately represented by DPO's	To what extent do you feel Disabled Peoples Organizations adequately represent your concerns and priorities? 1=Not at all; 2=A little; 3=Moderately; 4=Mostly; 5=Completely

*taken or adapted from the MDS

**adapted from the UNICEF MICS3 Questionnaire for Children Under Five; +adapted from the GALLUP annual Consumption Habits poll; ++adapted from the WHO Quality of Life-BREF

Publication 2

Open access Research

BMJ Open

Can propensity score matching be applied to cross-sectional data to evaluate Community-Based Rehabilitation? Results of a survey implementing the WHO's Community-Based Rehabilitation indicators in Vietnam

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ABSTRACT

Objectives Community-Based Rehabilitation (CBR) is a multi-sectoral approach working to equalise opportunities and include people with disabilities in all aspects of life. The complexity of CBR and often limited resources lead to challenges when attempting to quantify its effectiveness, with randomisation and longitudinal data rarely possible. Statistical methods, such as propensity score matching (PSM), offer an alternative approach to evaluate a treatment when randomisation is not feasible. The aim of this study is to examine whether PSM can be an effective method to facilitate evaluations of results in CBR when data are cross-sectional.

Design Cross-sectional survey.

Setting and participants Data were collected using the WHO's CBR Indicators in Vietnam, with treatment assignment (participating in CBR or not) determined by province of residence. 298 participants were selected through government records.

Results PSM was conducted using one-to-one nearest neighbour method on 10 covariates. In the unmatched sample, significant differences between groups were found for six of the 10 covariates. PSM successfully adjusted for bias in all covariates in the matched sample (74 matched pairs). A paired t-test compared the outcome of 'community inclusion' (a score based on selected indicators) between CBR and non-CBR participants for both the matched and unmatched samples, with CBR participants found to have significantly worse community inclusion scores (mean=17.86, SD=6.30, 95% CI 16.45 to 19.32) than non-CBR participants (mean=20.93, SD=6.16, 95% CI 19.50 to 22.35); t(73)=3.068, p=0.001. This result did not differ between the matched and unmatched samples.

Conclusion PSM successfully reduced bias between groups, though its application did not affect the tested outcome. PSM should be considered when analysing cross-sectional CBR data, especially for international comparisons where differences between populations may be greater.

Strengths and limitations of this study

- The complexity of CBR and often limited resources available in the field lead to challenges in research attempting to quantify its effectiveness and to a heavy reliance on non-randomised cross-sectional data, implying the need for statistical approaches, such as PSM, to account for these limitations.
- PSM attempts to mimic randomisation by creating a sample of participants who received the treatment (CBR participants) that is comparable on all observed covariates to participants who did not receive the treatment (non-CBR participants).
- The potential of using PSM for analysing cross-sectional CBR data was demonstrated, as biases detected in the distribution of covariates between groups in the unmatched sample were successfully eliminated.
- One of the main advantages of the CBR Indicators, namely the ability to use comparison individuals without disability from the community is lost; as PSM requires that all participants have a non-zero probability of receiving treatment meaning only people with disabilities can be included.
- PSM only controls for known covariates, which means that there is a potential for bias if some covariates that affect the outcome are not included.

INTRODUCTION

Community-Based Rehabilitation (CBR) is a multi-sectoral approach working to equalise opportunities and include people with disabilities in all aspects of community life. It is broadly defined as 'a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities'.[1] The wide scope of CBR is further expanded through the various implementing stakeholders involved in CBR, including people with disabilities themselves, their families and communities, and the relevant governmental and non-governmental service sectors. It is due, at least in part, to this extensive definition that reliable and internationally comparable data to monitor and evaluate CBR are scarce. In an effort to synthesise global perspectives on CBR, the WHO developed 'Community-Based Rehabilitation Guidelines' in 2010, which have since become accepted as a conceptual framework for CBR.[2] With these guidelines, WHO emphasised the need for a common global framework for monitoring CBR in line with the Convention on the Rights of Persons with Disability (CRPD). With the launch of the global WHO CBR Indicators in 2015, there is now a standardised approach to do this.[3 4]

The complexity of CBR leads to challenges in research when attempting to quantify its effectiveness.[5–7] Fully experimental studies with randomisation are rarely possible for both ethical and practical reasons, which inherently lead to limitations. The possibility of bias arises as the apparent difference in an outcome between two treatment groups may depend on characteristics that affected whether or not an individual received a given treatment, instead of being an actual effect of the treatment. For this reason there has been a recent emphasis on so-called natural experiments, where a range of primarily statistical approaches are used to evaluate a treatment or intervention when randomisation is not feasible.[8] One such approach is propensity score matching (PSM).

PSM was first presented in 1983 by Rosenbaum and Rubin as a method to reduce bias due to confounding variables in observational studies.[9] It attempts to mimic randomisation by creating a sample of participants who received the treatment that is comparable on all observed covariates to participants who did not receive the treatment. This effectively creates an experimental data set where the comparison group is, on average, equivalent to individuals in the exposed group on all observed covariates.[10–12] A systematic review comparing 21 PSM studies to 63 randomised controlled studies (RCTs) on therapeutic interventions for acute coronary syndromes found that PSM produced more extreme treatment effect estimates when compared with those from RCTs, although these differences were rarely statistically significant.[13] A similar comparison including 20 propensity-score-based studies matched to RCT results was conducted examining critical care medicine and found that propensity-score-based studies report less beneficial effects of treatment in comparison to RCTs.[14] Despite some shortcomings, PSM provides a method for evaluating complex interventions where randomisation is not possible.

PSM has been increasingly used in various research fields, including public health, to evaluate complex interventions.[15] CBR is considered a complex intervention, and data collection in the field is further hindered by low resources, making quantitative longitudinal data collection infeasible and rarely done.[6 7 16 17] This implies that data analysis in the field of CBR relies heavily on cross-sectional data. PSM has already been successfully applied to cross-sectional data.[18 19] Therefore, the main objective of this paper is to examine whether PSM can be an effective method to facilitate evaluations of results in CBR when data are cross-sectional. Data used in the present study were collected using the WHO CBR Indicators in Vietnam in 2016 with the assignment of persons to the treatment (CBR participants) and non-treatment group (non-CBR participants) determined by province of residence. PSM will be conducted on the outcome of *community inclusion* of people with disabilities, the ultimate goal of CBR in strong alignment with the CRPD, using a sum score of WHO CBR social indicators and an empowerment indicator.

METHODS

Data collection

Data collection was conducted using the survey questionnaire accompanying the WHO CBR Indicators.[3] These indicators examine differences in health, education, social life, livelihood and empowerment between people with disabilities and other community members. There are two subsets of indicators: base indicators which are broad and should be used in all data collection activities to ensure comparability, and supplementary indicators which can provide more specific coverage, and can be selected depending on the specific CBR goals and strategies of a programme. The indicators and corresponding questions used in this paper are presented in table 1.

This study presents a secondary analysis of data collected during a multi-site cross-sectional survey in 2016 in two Vietnamese provinces: Huế, where CBR is fully implemented and all districts have CBR coverage through government implementation and through non-governmental organisations' (NGO) activities; and Hòa Bình, where CBR is not implemented by either government or NGOs. The Huế CBR programme began in 2009 in cooperation with the Huế Rehabilitation Hospital. The programme focused mainly on activities to increase capacity building for CBR workers, not only in terms of rehabilitation skills, but also working to improve their counselling and networking skills. The other focus of the programme was to strengthen referral pathways for people with disabilities so that they could be connected with other existing services in the province, such as schools with teachers who were trained to support students with disabilities and vocational training centres. An Android mobile phone application (app), available from WHO for the CBR Indicators, was used to collect data during interviews (app free to download at: https://play.google.com/store/apps/details?id=com.universaltools.whocbr-survey&hl=en).

People with disabilities were identified prior to the survey by government records. In both provinces a team of five local healthcare workers were trained by the lead researcher (CM) over 2 days on how to conduct interviews

Table 1 WHO CBR Indicators and questions used to measure them

Component	Indicator	Survey Question
Social	**% of people with disability that feel valued as individuals by members of their community**	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?
	% of people with disability who 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)?
	% of people with disability who make their own decisions about their personal relationships	Do you get to make your own decisions about your personal relationships, such as friends and family?
	% of people with disability who participate in artistic, cultural or religious activities	Do you get to participate in artistic, cultural or religious activities?
	% of people with disability who participate in mainstream recreational, leisure and sports activities	Do you get to participate in community recreational, leisure and sports activities?
	% of people with disability who know their legal rights	To what extent do you know your legal rights?
Empowerment	**% of people with disability who make informed choices and decisions**	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?

Base indicators are shown in bold. The response option for all questions ranged from 1 (Not at all) to 5 (Completely).

using the survey questions and the app. Data collection was supervised by CM. Data were collected during face-to-face interviews with data recorded anonymously. All respondents were informed of the purpose of the study, and then provided verbal (Huế) or written consent (Hòa Bình). In Huế the decision to provide verbal rather than written consent was justified since requiring written consent would embarrass illiterate participants, leading to a decreased willingness to answer further questions truthfully. In instances when the respondent had cognitive limitations that prevented the respondent from being interviewed, or if the respondent was a minor, a proxy interview with a family member was performed.

Variables

Outcome Variable

To measure community inclusion, a sum score was created from the social base and supplementary questions, with the addition of the base question from empowerment. These questions all used the same response scale of *1 (Not at all)* to *5 (Completely)* with the final sum score ranging from 4 to 33, with higher scores indicating higher levels of inclusion (table 1).

Matching variables

Matching variables were those available from the WHO CBR Indicators, and were selected based on their theoretical association with community inclusion and CBR group assignment, primarily using CBR Guidelines.[2] Data on *age* and *gender* were collected. Age was collected in categories (see table 2), which were dichotomised for the analysis.[20] Though data on disability severity were not available, *general health status* was used as a proxy, using the question *'How would you rate your health today?".*[21] A variable for *socio-economic status* (SES) was created using a sum score based on the questions '*What is the highest level of education you have achieved or are working to achieve?'* and '*Do you have enough money to meet your needs?"*. The first question is commonly used in SES variable creation, and the second question targets wealth.[22 23] The variable *province of residence* corresponded to CBR coverage (no coverage in Hòa Bình, full CBR coverage in Huế). To account for economic differences between the provinces that might not be captured by SES, the covariate *receiving social protection* (such as for loss of income through old age, sickness or disability) was included. Covariates of *financial awareness* (knowing how to get financial services or social protection if needed), *having access to health services when needed,* and *having access to rehabilitation services when needed* were also included. A proxy for autonomy was captured through the covariates of *being involved in decision making regarding medical treatment* and *participating in a self-help group if desired* (see online supplementary table). Seeing as the CBR programme in Huế focused on increasing referral pathways within the medical and education sectors, the questions derived from the education component and many from the medical component were not included as matching variables, since including covariates associated with CBR participation but not with community inclusion decrease model precision.[24]

Missing data

Missing data were low (2.25%). Multiple imputation (five imputations) using fully conditional specification (MICE package[25] in R Studio Version 0.99.903) was used to replace missing data.

Table 2 Baseline characteristics of CBR participants and non-CBR participants in the unmatched and matched samples

Variable	Unmatched Sample No CBR (n=151)	With CBR (n=147)	Std. dif. of means	Matched Sample No CBR (n=74)	With CBR (n=74)	Std. dif. of means
Age						
0–5	11 (7.2%)	6 (4.1%)	0.161	3 (4.1%)	5 (6.8%)	0.136
6–12	19 (12.6%)	11 (7.5%)	0.193	7 (9.5%)	5 (6.8%)	0.102
13–17	4 (2.6%)	6 (4.1%)	0.072	2 (2.7%)	1 (1.4%)	0.068
18–24	12 (7.9%)	12 (8.2%)	0.008	7 (9.5%)	7 (9.5%)	0.000
25–44	49 (32.5%)	32 (21.8%)	**0.258**	23 (31.1%)	22 (29.7%)	0.033
45–64	42 (27.8%)	44 (29.9%)	0.046	21 (28.4%)	26 (35.1%)	0.147
65+	14 (9.3%)	36 (24.5%)	**0.353**	11 (14.9%)	8 (10.8%)	0.094
Gender (male)	80 (53.0%)	73 (50.0%)	0.066	37 (50.0%)	42 (56.8%)	0.135
SES (range 1–10)	3.74±1.32	3.91±1.30	0.235	3.65±1.45	3.67±1.42	0.020
Health status (range 1– 5)	2.89±0.77	3.37±0.70	**0.683**	3.05±0.75	3.14±0. 65	0.115
Receiving social protection	74 (49.0%)	117 (79.6%)	**1.008**	48 (64.9%)	52 (70.3%)	0.141
Access to health services	132 (87.4%)	126 (85.7%)	0.048	66 (89.2%)	66 (89.2%)	0.000
Access to rehabilitation services	128 (84.8%)	123 (83.7%)	**0.263**	29 (39.2%)	31 (41.9%)	0.054
Self-help group	63 (41.7%)	75 (51.0%)	**0.396**	31 (41.9%)	32 (43.2%)	0.027
Financial awareness	73 (48.3%)	122 (83.0%)	**0.789**	51 (68.9%)	55 (74.3%)	0.134
Involved in treatment decisions	47 (31.1%)	65 (44.2%)	0.137	65 (87.8%)	65 (87.8%)	0.000

Absolute standardised differences of means are shown, with differences exceeding the threshold of 0.25 indicated in bold.
Note: continuous variables are presented as means ± SD; dichotomous variables are presented as n(%).

Analysis

Matching on the propensity score

The number of treated and untreated participants were similar (difference of n=4). Therefore, participants were matched using one-to-one nearest neighbour technique, which matched each treated unit to one control that was closest using callipers of width equal to 0.25 of the SD of the logit of the estimated propensity score without iteration.[26] This implies that for a given treated participant, all the untreated participants are identified whose scores are within this specified distance and then the best match is formed. If no match falls within this distance the participant is excluded. Participants were matched on ten covariates (see *Matching Variables*).

Balance diagnostics

Baseline comparisons between the covariates were conducted for the matched and unmatched samples. Balance diagnosis was performed using the standardised difference method, which compares the difference in means of each covariate in units of the pooled SD for the matched and unmatched samples.[12] Successful matching is indicated when the absolute standardised differences of means is less than 0.25.[27]

Comparing groups

For the community inclusion outcome, data matched on the ten covariates were compared using a paired t-test.[28] Bootstrapping was performed (1000 samples) in order to produce 95% confidence intervals (CI), which has been shown to account for uncertainty in the matching procedure.[20]

A sensitivity analysis was performed using the Rosenbaum Bounds for Hodges-Lehmann Point Estimate to assess how robust the findings were to hidden bias due to unobserved covariates (‘rbounds’ package[29] in R Studio Version 0.99.903). The maximum Gamma (the odds of differential assignment to treatment due to unobserved factors) was set to two with increments of 0.1 to test at which point the between group differences are no longer robust.[29]

Data cleaning was performed using SPSS V,23 (copyright IBM Corporation). PSM was performed in R Studio (Version 0.99.903) using the ‘MatchIt’ package.[30]

Patient and public involvement

Participants were not directly involved in the development of the research question, study design, recruitment or conduct of the study. However, in the province of Huế (where CBR is implemented), participants are continually involved in the development of the CBR programme, as CBR is participatory in nature. It was through their motivation—stemming from the need to prove to the national government and international donors that their intervention has an impact in order to receive funds—that the survey was conducted in the first place. A study report was submitted to the Huế and Hòa Bình Ministries of Health, which presented simple numeric and graphic descriptive findings which were to be communicated to participants.

RESULTS

Data were available from 298 participants. In Huế, 575 people with disabilities were identified by government records and 147 were included, while in Hòa Bình 375 people were identified by government records and 151 were included (sample size calculated using an alpha significance level of 0.05 and power of 90%). Included participants were randomly selected from the complete list. After the random selection, each interviewer was assigned a group of selected participants based on their geographic location. Of the randomly selected participants, one in Hòa Bình could not be contacted so another participant was selected. In both provinces, none of the invited participants refused participation. Males comprised 153 (51.3%) of the participants, with a modal age group of 45–64 (28.9%) (see table 2 for further descriptives).

In the unmatched sample, CBR participants had higher health status, were more likely to participate in a self-help group, more financially aware and more likely to be receiving social protection, while they had worse access to rehabilitation services. Some age differences were also noted (table 2). In the unmatched sample the absolute standardised difference across the 10 covariates ranged from 0.008 to 1.008 indicating bias.

When CBR participants were matched with non-CBR participants on the logit of the specified propensity score model, 74 matched pairs were formed. This meant that 49.7% of CBR participants were successfully matched to a control. PSM was successful in reducing bias between the covariates in the matched sample, as the standardised differences ranged from 0 to 0.147 with all values falling below the threshold value of 0.25[27] (table 2).

To test whether PSM affected the pre-defined outcome of community inclusion, the difference between groups in the matched and unmatched samples were assessed; similar significant differences were found. In the matched sample, CBR participants had worse community inclusion scores (mean=17.86, SD=6.30, 95% CI 16.45 to 19.32) than non-CBR participants (mean=20.93, SD=6.16, 95% CI 19.50 to 22.35); t(73)=3.068, p=0.001. The sensitivity analysis corroborated the results, showing that CBR participants had a median difference in community inclusion score 3.5 points lower than non-CBR participants (Gamma=0). When the Gamma value was increased to 2, the upper and lower bounds did not include zero, indicating robust results.[29] In a further sensitivity analysis, to ensure that the covariate of 'access to rehabilitation' did not bias the model by being more strongly associated with receiving CBR rather than with the outcome of community inclusion, the model was run excluding this variable. The new model resulted in 75 matched pairs with all standardised differences falling below the threshold. The results of the t-test did not differ from the model including access to rehabilitation; CBR participants had worse community inclusion scores (mean=18.11, SD=5.981, 95% CI 16.72 to 19.47) than non-CBR participants (mean=21.17, SD=6.381, 95% CI 19.67 to 22.60); t(74)=3.310, p=0.0014.

Overall, the results did not differ from the results before PSM: community inclusion for participants with CBR (mean=18.61, SD=5.38) and without CBR (mean=20.64, SD=6.49); t(296)=2.935, p=0.004 using an independent t-test.

DISCUSSION

To our knowledge, this study presents the first use of PSM as a method for analysing cross-sectional data in the field of CBR. The study analysed data collected using the WHO CBR Indicators and found that community inclusion scores of CBR participants were significantly lower than those of non-CBR participants after PSM. Despite bias being detected in the distribution of covariates between groups in the unmatched sample, the results before PSM did not significantly differ from those after. We conclude that PSM can be successfully applied to cross-sectional CBR data, though in this case the bias reduction provided by PSM did not affect the tested outcome.

PSM has been applied only to longitudinal CBR data so far, but PSM studies using cross-sectional data are available from other fields. These studies had similar results in terms of the methodological success of PSM, but unlike our study they had final outcomes in line with their hypotheses. One such example is the study from Jalan and Ravallion, which examines the effect of an employment-based poverty reduction programme on income gain, accounting for pre-intervention and foregone income.[19] Through the trial of three PSM methods, they were able to reduce the differences between the two populations and to demonstrate the effectiveness of the programme. Another such example is the study from Becerril and Abdulai showing the positive impact of new maize farming technologies on per capita poverty outcomes.[18] Similar to our study, they detected bias in the distribution of covariates between groups in the unmatched sample, indicating that accounting for bias though PSM was important. In the field of CBR, PSM has been used to evaluate longitudinal CBR data in India, looking at livelihood and health outcomes.[31 32] PSM was used to reduce the bias between the CBR and non-CBR groups, with results showing that CBR participants had better health and livelihood outcomes, and that these differences generally increased over time at both 4 years and 7 years. In our study, data were collected 7 years after the programme began, which would make the timing comparable and it is therefore plausible that the effect of CBR in our study could already be quantifiable. As in our study, these studies all showed bias between unmatched groups, which were reduced in the matched sample after PSM. However, none of these studies presented their outcome results of the unmatched sample for comparison, so it cannot be determined if their final results were unaffected by matching as is the case in our study.

The results of the present study go against the anecdotal evidence that CBR has a positive influence on the lives of people with disabilities.[6 7 33] Results from longitudinal data indicate that CBR has a positive impact on receiving pensions, accessing paid jobs, accessing assistive devices and personal-practical autonomy, with the impact increasing over time.[31] An explanation for our results could be that cross-sectional data allow for comparisons between groups at a single time point, and even after PSM is applied to reduce bias the causal relationship between CBR implementation and social inclusion cannot be determined. While the cross-sectional data collected in this study represent the first quantitative data from the region and therefore an important foundation for future work, the results emphasise the general need for further collection and publication of CBR data, especially longitudinal data. Additionally, this study focused on community inclusion—the ultimate goal of CBR—but when interpreting results it is also important to consider the specific targets of the programme being examined. Though CBR aims to impact all aspects of the lives of people with disabilities to increase community inclusion, the programme in Huế does not directly target community inclusion. The programme focuses on increasing the capacity of CBR workers and on strengthening referral pathways with the medical and educational sectors. Through these activities, the community inclusion of people with disabilities should improve over time, but since community inclusion was not the direct target of the programme, the community inclusion effects might only appear after a longer period, which could be a reason for the counter-intuitive results. Therefore, when assessing a programme in its early stages, it may be more important to match the indicators used with the specific targets of programmes.

To our knowledge, this study is the first to implement the recently developed WHO CBR Indicators.[4] The study highlights how important it is to collect standardised data in the field of CBR in order to facilitate comparisons between groups and determine effectiveness of programmes. One of the main advantages of the CBR Indicators and their data collection strategy is that they are easy to use in the field. The indicators allow for descriptive comparisons to be made easily, but in order for indicators to be used appropriately, it is important to go beyond these descriptive results using inferential statistics. Furthermore, no single indicator or even a set of indicators is capable of capturing all changes in dynamic settings. The use of indicators alone has the potential limitation of collecting meaningless or misleading information,[34] and therefore they should be used as part of a broad evaluation strategy, in combination with qualitative and participatory evaluations.[33] Another way to reduce the limitations arising from indicator use is to continually test and re-assess the indicators.[34] In the case of the CBR Indicators, a priority should be to do this in partnership with communities and people with disabilities in order to promote their uptake.

The use of PSM as a method for analysis of cross-sectional data collected from the CBR Indicators is conceptually strong, due to its ability to reduce bias due to confounding variables in observational studies.[9] However, the methodological limitations of PSM also need to be considered. PSM requires that each participant has a non-zero probability of receiving treatment, meaning only people with disabilities can be included in the analysis. Due to this, one of the main advantages of the CBR Indicators, namely the ability to use comparison individuals from the community, is lost.[4] Furthermore, PSM only controls for known covariates, which means that there is a potential for bias if some covariates that affect the outcome are not included.[9] For example, in this study no data were available on the ethnicity of participants, despite its known association with social disparities in Vietnam.[35] Another such covariate in this study could be disability severity, although this was partially adjusted for in both the participant selection, whereby all people with disabilities were identified using the same government disability criteria, and further in the analysis through the inclusion of the self-rated health covariate. Another limitation of PSM is that it leads to reduced sample size, which could limit generalizability, though this is partly addressed through the provided sensitivity analysis. The reduced sample size also increases the risk of type II error,[36] but the sample size of this study met the commonly recommended minimum sample size of 10(p+1), where p is the number of matching variables.[37] This study presents a starting point to encourage the generation of quantitative CBR research and demonstrates one possible method for reducing bias when analysing cross-sectional CBR data. Further studies should look into additional statistical methods for analysing the results obtained from the CBR Indicators.

Based on the present study, we recommend the further use and testing of the WHO CBR Indicators to increase standardised data collection in the field of CBR. In accompaniment to increased data collection, we recommend PSM as a method to reduce bias in cross-sectional CBR data analyses, especially for international comparisons where differences between populations may be greater than the within country differences observed in this study. Since using cross-sectional data presents limitations even after adjusting for bias, we also emphasise the need for future longitudinal data collection in order to assess effectiveness in the field of CBR.

CONCLUSION

This study presents the first use of PSM as a method for analysing cross-sectional CBR data. While randomised and longitudinal data are ideal for evaluations, cross-sectional data presents the advantage of being more feasible to collect and thereby provides an essential foundation to generate hypotheses and perform further studies.

Therefore, it is essential that appropriate statistical methods are applied to capitalise on available data. The potential of using PSM for analysing cross-sectional CBR data was demonstrated, though further research should investigate alternative inferential methods, such as cluster matching or adjusted regression, which may be more suitable in allowing for the comparison of the differences between persons with and without disabilities in line with the WHO CBR Indicators. We recommend that the questions and indicators be continually reviewed, and that future cross-sectional CBR studies use PSM to reduce bias when comparing groups.

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Publication 3

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ORIGINAL ARTICLE

What predictors are associated with the social inclusion of people with disabilities? A comparison of community-based rehabilitation participants to the general population in Vietnam

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ABSTRACT

Purpose: To estimate which predictors from the World Health Organization's Community-Based Rehabilitation (CBR) Indicators have the strongest association with the social inclusion of people with disabilities who participate in CBR compared to the general population.

Methods: Data were collected using the CBR Indicators survey in Vietnam, including both CBR participants and the general population. A social inclusion score was created using seven questions covering the domains of interpersonal relationships and community participation. Additional questions were used as predictors and were grouped into five theoretical categories: sociodemographic, health, education, livelihood, and empowerment. Multivariate linear regression was used to show which predictors had a significant association with social inclusion.

Results: Seven predictors (one health, three livelihood, and three empowerment) explained 70.9% of the variance in social inclusion for CBR participants and seven predictors (two health, one education, three livelihood, and one empowerment) explained 58.8% of the variance for the general population. Age, gender, education, employment, and self-rated health had non-significant associations in both populations.

Conclusions: Livelihood and empowerment predictors showed the strongest association with social inclusion of CBR participants, and livelihood predictors for the general population. CBR programs should emphasize livelihood and empowerment activities to increase social inclusion of people with disabilities.

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➤ IMPLICATIONS FOR REHABILITATION

- Social inclusion is a human right which has emerged as a major priority in the United Nation's Sustainable Development Goals.
- People with disabilities continue to experience low levels of social inclusion.
- It is important to determine which factors have the greatest impact on the social inclusion of people with disabilities.
- Although Community-Based Rehabilitation programs are often health focused, this study found that empowerment and livelihood predictors had the greatest association with social inclusion.
- Programs aiming to improve the social inclusion of people with disabilities should target empowerment and livelihood issues.

Introduction

Social inclusion is a human right which has emerged as a major priority in the United Nation's Sustainable Development Goals, with social exclusion of minority and marginalized groups being recognized as one of the greatest hindrances to achieving these goals [1–3]. The World Bank Group defines social inclusion as "the process of improving the terms on which individuals and groups take part in society – improving the ability, opportunity, and dignity of those disadvantaged on the basis of their identity" [4]. The effects of social inclusion are widespread, with the impact extending to outcomes of health and well-being [5–8], poverty, education, and crime [9], as well as having direct biological [10] and behavioral effects [11]. The Sustainable Development Goals emphasize the importance of addressing traditional stereotypes toward minority groups that still influence their social inclusion [4,9]. One of the most marginalized groups is people with disabilities, and due to this, social inclusion is a key component of the United Nations Convention on the Rights of Persons with Disabilities [2,12].

Despite the growing recognition of the importance of social inclusion, the concept of social inclusion is complex and even controversial in nature [13]. Attempting to understand and define social inclusion requires integration of the fields of sociology, history, economics, psychology, and the natural sciences, which has led to diverse uses of the term in the literature [14]. From a sociological perspective, social inclusion – and the stratification, ordering and divisions in society that hinder it – is historically embedded in human society [14]. While historically social inclusion has been defined in regards to social exclusion, social inclusion as a distinct concept rose to prominence in France in the 1970s [15]. This paradigm shift led to an increased interest in

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community, inclusivity, and social solidarity. Since then, the various schools of thought continue to debate the interconnectedness and conceptualization of these ideas [14,15], which is further impeded by the lack of clear boundaries to the topic.

As the definition of social inclusion is still debated in the literature, quantifying social inclusion is particularly challenging. Furthermore, the multi-dimensional and interactive process of social inclusion implies that the predictors of social inclusion partly coincide with the definition itself [13,16]. Even the perception and discussion of stratifications of society when attempting to understand social inclusion can lead to further divisions [14]. In the past, social inclusion and exclusion have sometimes been equated to poverty, and though they are strongly linked, it has been shown that poverty is not interchangeable with social inclusion or exclusion [17,18]. A few initiatives have attempted to operationalize social inclusion using varying definitions, though the majority are purely economic or poverty focused and most lack validation [18,19]. In addition to economic and poverty terms, other reoccurring domains when defining social inclusion include perceived opportunities, basic human needs, well-being, interpersonal relationships, and social networks (e.g., [19–23]). One such action in the field of disability is the review by Simplican et al., which conceptualizes and presents a model of the factors of social inclusion specific to the field [23].

People with disabilities continue to experience low levels of social inclusion [24,25]. In efforts to address this, agencies such as the World Health Organization (WHO) promote social inclusion through various action plans, policies and strategies (e.g., [26–28]). One such strategy is Community-Based Rehabilitation (CBR). CBR is a multi-sectoral approach working to equalize opportunities and include people with disability in all aspects of community life. It is defined as “a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities” [29]. The wide scope of CBR is further broadened through the various implementing bodies involved in CBR, including people with disabilities themselves, their families and communities, and the relevant governmental and non-governmental service sectors. Although the definition is broad and the associated stakeholders are vast, the ultimate goal of CBR is to lead to the inclusion of people with disabilities into all aspects of community life [29,30].

Though CBR has been promoted as a strategy by the WHO and other international organizations since the 1970s, reliable and internationally comparable data to quantify the effect CBR has on the lives of people with disabilities is scarce [26,31–33]. Furthermore, existing assessments of CBR often focus on health or education outcomes [33] rather than the ultimate goal of CBR, namely, social inclusion. In an effort to address the lack of standardized CBR data, the WHO developed a set of global CBR Indicators as a means to collect standardized quantitative data [34,35]. The WHO CBR Indicators were developed with the goals of:

1. being generic in that they can be used independently of the specific objectives and activities of individual CBR programs anywhere in the world; and
2. allowing for comparison between persons with and without disabilities living in the same community.

The indicators examine differences in health, education, social life, livelihood, and empowerment between people with disabilities and other members of the community. These different components are all linked to social inclusion; though it is unknown which of these factors have the greatest influence on social inclusion [36].

This paper aims to estimate which predictors, captured using the WHO CBR Indicators, have the greatest association with the social inclusion of CBR participants, and to compare the findings to those of the general population in Vietnam.

Methods

Data collection

This study presents a secondary analysis of data collected in 2016 in the Vietnamese province of Huế using the survey questionnaire accompanying the WHO CBR Indicators [34]. The mobile phone app, available from WHO for the CBR Indicators, was used to collect data during at-home interviews (app free to download from Google Play Store). There are two subsets of indicators in the survey: base indicators which are broad and should be used in all data collection activities to ensure comparability, and supplementary indicators which can provide more specific coverage, and can be selected depending on the specific CBR goals and strategies of a program.

In Huế, CBR is fully implemented, and all districts have CBR coverage through government implementation and through non-governmental organizations’ activities. CBR participants identified prior to the survey through the comprehensive government database of persons with disabilities. Of the 575 registered CBR participants in the area, 150 were selected at random for inclusion. For every CBR participant, a comparison individual of the same gender and similar age was selected from a neighboring household. A team of five local health care workers were trained and supervised by the lead researcher (CM). Data were recorded anonymously and all respondents were informed of the purpose of the study and provided consent. In instances when the respondent had cognitive limitations that prevented them from being interviewed, or if the respondent was a minor, a proxy interview with a family member was performed. Ethical approval was obtained

Table 1. WHO CBR Indicators and corresponding questions for creation of the social inclusion sum score.

Variable	Measure
Feel valued in community	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?
Make personal assistance decisions	Do you get to make decisions about the personal assistance that you need (who assists you, what type of assistance, when to get assistance)?
Make personal relationship decisions	Do you get to make your own decisions about your personal relationships, such as friends and family?
Participate in cultural activities	Do you get to participate in artistic, cultural or religious activities?
Participate in recreational activities	Do you get to participate in community recreational, leisure and sports activities?
Aware of legal rights	To what extent do you know your legal rights?
Make informed decisions	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?

All responses ranged from 1 *(Not at all)* to 5 *(Completely)*. Variables derived from base indicators are bolded.

Table 2. Predictor variables from the WHO CBR indicators presented in their theoretical categories with their corresponding questions and analysis categories.

Predictor	Survey question and response options	Analysis categories
Sociodemographic		
Gender	Record the gender of the selected participant	Male = 1, Female = 0
Age	How old are you?	0–5 yrs = 1; 6–12 yrs = 2; 13–17 yrs = 3; 18–24 yrs = 4; 25–44 yrs = 5; 45–64 yrs = 6; 65 + yrs = 7
Employment grade	What is your current working situation? *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; 4 = Working for wages, but currently on sick leave; 5 = Self-employed or own-account worker; 6 = Working as unpaid family member; 7 = Retired because of the health condition; 8 = Retired because of age; 9 = Early retirement; 10 = Other*	If respondent answered 1: score = 0 If respondent answered 6: score = 1 If respondent answered 2, 3, 4, 5, 7, 8, 9: score = 2 If respondent answered 10: score = missing
Education level	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*	If respondent answered 1: score = 0 If respondent answered 2: score = 1 If respondent answered 3, 4, 5: score = 2[a] If respondent answered 6, 7, 8: score = 3
Health		
Self-rated health	In general, how would you rate your health today? *1 = Very good; 2 = Good; 3 = Neither poor nor good; 4 = Poor; 5 = Very poor*	Inverted
Treated with respect by health service providers	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)*	No transformation
Aware of health prevention measures	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*	If respondent answered 1: score = 1 If respondent answered 2: score = 0
Received needed 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 in the past 12 months*	If respondent answered 1: score = 0 If respondent answered 2 or 3: score = 1
Involved in making treatment decisions	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)*	No transformation
Received needed rehabilitation services	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 in the past 12 months*	If respondent answered 1: score = 0 If respondent answered 2 or 3: score = 1
Have appropriate assistive devices	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? Any visual aids, such as glasses or a white cane? 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*	If respondent answered 1 or 5 to all questions: score = 1 If respondent answered 2, 3 or 4 to any question: score = 0
Education		
Participate in educational activities	Do you participate in learning opportunities to improve your skills for everyday life or work? *1 = Yes; 2 = No*	If respondent answered 1: score = 1 If respondent answered 2: score = 0
Enjoy educational activities	To what extent does it fit your needs? *1 (Not at all); 2; 3; 4; 5 (Completely)*	No transformation
Livelihood		
Have enough money	Do you have enough money to meet your needs? *1 (Not at all); 2; 3; 4; 5 (Completely)*	No transformation
Make financial decisions	Do you get to decide how to use your money? *1 (Not at all); 2; 3; 4; 5 (Completely)*	No transformation
Aware of financial services	Do you know how to get financial services such as credit, insurance, grants, and savings programs? *1 = Yes; 2 = No*	If respondent answered 1: score = 1 If respondent answered 2: score = 0
Receive financial aid	Do you currently benefit from any social protection program, such as loss of income through old age, sickness or disability? *1 = Yes; 2 = No*	If respondent answered 1: score = 1 If respondent answered 2: score = 0
Aware of social services	Do you know how to get social protection against loss of income resulting from old age, sickness or disability? *1 = Yes; 2 = No*	If respondent answered 1: score = 1 If respondent answered 2: score = 0

(*continued*)

Table 2. Continued.

Predictor	Survey question and response options	Analysis categories
Empowerment		
Aware of disability rights	Do you think that the policies in your country provide people with disability equal rights as other people? *1 (Not at all); 2; 3; 4; 5 (Completely)*	No transformation
Communication satisfaction	Are you satisfied with your ability to persuade people of your views and interests? *1 (Not at all); 2; 3; 4; 5 (Completely)*	No transformation
Able to influence community	Do you get to influence the way your community is run? *1 (Not at all); 2; 3; 4; 5 (Completely)*	No transformation
Politically aware	Did you vote in the last election? *1 = Yes; 2 = No*	If respondent answered 1: score = 1 If respondent answered 2: score = 0
Participation in self-help group	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*	If respondent answered 1 or 3: score = 1 If respondent answered 2: score = 0

Variables derived from base indicators are bolded.

[a]Vocation and professional training were both understood as job-based training and therefore scored equally.

through the Ludwig-Maximilians-Universität Munich Ethics Commission and locally by the provincial Department of Health.

Outcome variable and predictors

Operationalizing social inclusion remains a challenge. In the field of disability, the review by Simplican et al. [23] presents an ecological model with two major domains – interpersonal relationships and community participation – to define social inclusion, which is used as a guide for its operationalization in this study. Based on this, a social inclusion sum score was created from six social life (base and supplementary) and one empowerment (base) CBR Indicators. This included the indicators of personal assistance, personal relationships, and making decisions to cover interpersonal relationships; and the indicators of feeling valued, participation in cultural activities, participation in recreational activities and legal rights to cover community participation. These seven survey questions used the same response scale of *1 (Not at all)* to *5 (Completely)* (Table 1).

The CBR Indicator survey questions were also used as predicator variables for the model. The 23 questions used as predicators were grouped into five theoretical categories for increased comprehensibility of the results: sociodemographic, health, education, livelihood, and empowerment (Table 2). Questions from the CBR Indicator survey that were flagged as problematic during data collection (five questions) or targeted a subpopulation (two questions) were not included.

Analysis

Multiple imputation (five imputations) using fully conditional specification (chained equations imputation) was used to replace missing data using the MICE package in R Studio Version 0.99.903. All other analyses were performed using SPSS version 23 (copyright IBM Corporation, Armonk, NY).

Correlations were examined to decide which variables would be used to predict social inclusion. All variables that were significantly correlated with social inclusion (Spearman's rho, $p < 0.05$) were included in the backward deletion multivariate linear regression. These steps were performed separately for CBR participants and the general population.

F-tests were used to compute the significance of the removed variables, with the stepping criterion for removal set to $p \geq 0.10$. Further, the resulting change in the adjusted R^2 was tested at $p < 0.05$ to check if it was significantly different from zero. Linearity of association between the predictors and social inclusion was ensured using the one-way analysis of variance test of linearity, followed by examination of residuals scatterplots which found no important deviations from the assumptions of normality and linearity. Additionally, the restriction to any education (>no education) and to adults (≥18 years) were performed.

Results

Data were available from 147 CBR participants (50.3% female) and 152 members of the general population (48.7% female). The age distribution of CBR participants was similar to that of the general population (15.6% vs. 15.1% under 18 years, 29.9% vs. 24.3% 18–44 years, 54.4% vs. 61.2% over 44 years, respectively). CBR participants reported lower levels of completed education compared to the general population (46% vs. 12% with no education, respectively) and were less likely to work for wages or be self-employed (8% vs. 40%, respectively). The overall social inclusion

Table 3. Spearman's rho correlations (ρ, unadjusted) between social inclusion score and predictors for CBR participants and the general population.

Theoretical category	Predictor	CBR participants (ρ)	General population (ρ)
Socio-demographic	Gender	0.113	–0.030
	Age	0.167*	–0.087
	Employment grade	0.327**	0.330**
	Education level	0.327**	0.330**
Health	Self-rated health	0.073	0.282**
	Treated with respect by health service providers	0.115	0.491**
	Aware of health prevention measures	†	0.311**
	Received needed medical care	0.205*	0.303**
	Involved in making treatment decisions	0.446**	0.583**
	Received needed rehabilitation services	0.083	0.274**
	Have appropriate assistive devices	0.046	0.374**
Education	Participate in educational activities	0.291**	0.414**
	Enjoy educational activities	0.227**	0.250**
Livelihood	Have enough money	0.392**	0.503**
	Make financial decisions	0.699**	0.619**
	Aware of financial services	0.364**	0.201*
	Receive financial aid	0.583**	0.250**
	Aware of social services	0.135	–0.219**
Empowerment	Aware of disability rights	0.436**	0.464**
	Communication satisfaction	0.506**	0.396**
	Able to influence community	0.397**	0.405**
	Political awareness	0.328**	0.084
	Participation in self-help group	0.069	–0.090

*Significant at the 0.05 level (two-tailed).

**Significant at the 0.01 level (two-tailed).

†All CBR participants had the same response to this question (all had positive responses).

Table 4. The predictors selected through the backwards elimination regression model for CBR participants and for the general population.

Category	Predictor	Beta	Sig.	Tolerance
CBR participants				
	Constant		0.588	
Health	Involved in making treatment decisions	0.25	<0.001	0.671
Livelihood	Make financial decisions	0.30	<0.001	0.495
	Aware of financial services	0.11	0.044	0.658
	Receive financial aid	0.14	0.016	0.579
Empowerment	Aware of disability rights	0.13	0.021	0.608
	Communication satisfaction	0.27	<0.001	0.430
	Able to influence community	0.13	0.014	0.709
General population				
	Constant		0.001	
Health	Treated with respect by health service providers	0.16	0.024	0.596
	Involved in making treatment decisions	0.14	0.050	0.528
Education	Participate in educational activities	0.21	0.001	0.760
Livelihood	Have enough money	0.11	0.097	0.652
	Make financial decisions	0.33	<0.001	0.544
	Aware of social services	–0.13	0.016	0.907
Empowerment	Aware of disability rights	0.12	0.062	0.666

Stepping criteria: $p \geq 0.10$ to remove and adjusted R^2 change associated with the predictor to be $p > 0.05$.

sum score ranged from 7 to 33, with higher values indicating better levels of inclusion.

Table 3 presents the correlations between the 23 predictors and social inclusion for CBR participants and the general population. Eight of these variables in CBR participants (gender, self-rated health, treated with respect at health service provider, health prevention, rehabilitation services, assistive devices, aware of social services, participation in self-help group) and four in the general population (gender, age, political awareness, participation in self-help group) were not significantly associated with social inclusion and were therefore not considered in further analyses. The measures most strongly related to social inclusion in bivariate analysis for CBR participants were making financial decisions, receiving financial aid, and communication satisfaction; and for the general population making financial decisions, involved in treatment decisions, and having enough money.

Table 4 presents the results of the backwards elimination multivariate linear regression for CBR participants and the general population. For CBR participants, seven predicators met the stepping criteria and explained 70.9% of the variance in social inclusion. Of these seven predictors, none from the theoretical category of sociodemographic or education were included, while one health, three livelihood, and three empowerment predictors were included. In the general population, seven predictors explained 58.8% of the variance in social inclusion. These seven predictors fell into slightly more diverse theoretical categories: two health, one education, three livelihood, one empowerment, and none of the sociodemographic predictors. Making financial decisions had the greatest weighting on social inclusion for both populations (Beta CBR participants = 0.30, general population = 0.33). For CBR participants, communication satisfaction also had a large weighting (Beta = 0.27). All predictors were categorized with higher values having positive weighting, though interestingly, being aware of how to get social service benefits was a negative predictor of social inclusion for the general population.

Multicollinearity was analyzed using tolerance statistics, with no problems detected as all tolerance levels were above 0.40. Limiting the model to only those with any education did not significantly affect the inclusion of predictors in the theoretical categories or the model fit. Limiting the model to only adults did not greatly change distribution of predictors in the theoretical categories for the general population, but it did reduce the number of predictors included and fit of the CBR participant model (the health predicator and livelihood predictor of "aware of financial services" were no longer included).

Discussion

Understanding the factors that influence social inclusion is of great importance as social inclusion is linked to a wide range of outcomes including health and well-being, poverty, education, and employment, amongst others [5–9]. For people with disabilities, who often face exclusion due to stereotyping and a lack of access to services, strategies that aim to promote their social inclusion, such as CBR, are highly relevant. Since CBR is such a diverse strategy, determining which predictors influence the social inclusion of CBR participants presents the opportunity to tailor CBR efforts to maximize effectiveness for the social inclusion of people with disabilities.

To our knowledge, this is the first study to examine the predictors affecting social inclusion in CBR participants, and furthermore to compare the results to that of the general population. Our results show that livelihood and empowerment aspects have the greatest association with social inclusion for CBR participants; of the seven predictors included in the model 3 were livelihood related, three empowerment related and one health related. In contrast, the predictors for the general population were slightly more diverse; of the seven predictors included two were health related, one education, three livelihood and one empowerment.

These results quantitatively emphasize what is already known – that poverty (represented here through livelihood predictors) has a strong association with social inclusion as it leads to a lack of resources, which can prevent people from integrating into what would be considered their social roles [4,16,37]. Interestingly, the livelihood predictor of having enough money, perhaps the most direct predictor of poverty, was not included in the CBR participant model but included in the general population model. Instead, making financial decisions had the greatest weighting on social inclusion for both populations (Beta CBR participants = 0.30, general population = 0.33). While livelihood is strongly associated with social inclusion in both populations, empowerment – and in particular the communication satisfaction (Beta = 0.27) – was significant for people with disabilities, emphasizing the empowerment discrepancy between people with disabilities and the general population.

There were some unexpected results, as a few predictors which were shown to be related to social inclusion in the literature did not meet the criteria to be included in our models. Barnes et al. found that poor health was related to cultural activity participation and social relationships, and that gender and low income were also related to cultural activity participation in the over 50-year old English population [38]. Levitas et al. also found that social participation was linked to health, though only moderately [39]. In contrast to this, our study found that self-rated health, gender and having enough money did not affect social inclusion in either population. A systematic review found that access to assistive technology was highly related to social engagement in persons with intellectual disabilities [40], while our study did not find a significant association between access and use of assistive devices to social inclusion. This review also found that opportunities to make choices and opportunities for autonomy positively affected social participation [40]. This is in line with our findings, as the most influential predictors (making financial decisions, communication satisfaction) have strong elements of autonomy.

When interpreting the results, it is imperative that the limitations arising from the use of cross-sectional data are considered – no causality between the predictors and the outcome can be assumed. Also, the generalizability of the results could be impaired as this study was limited to a single province in Vietnam. This is especially true as social inclusion is a concept relative to culture and to individual communities [9,41]. However, this emphasizes one of the strengths of this study, in that the two groups came from the same community, allowing for comparability.

Another important limitation of this study stems from the fact that the definition of social inclusion itself is still debated in the literature, and furthermore the multi-faceted and interactive concept of social inclusion implies that the predictors of social inclusion partly coincide with the definition itself [16]. When measuring a complex concept such as social inclusion, the challenge is that there is no direct way to measure the concept. Instead, clearly definable outcomes (such as employment, education, and self-rated measures) can be used even though they do not fully capture the concept. In general, the few existing measures of social inclusion lack psychometric validation [19] or are focused almost solely on economic outcomes, though social inclusion is broader than just poverty [17,18,39]. Our study attempts to capture social inclusion based on the availability of the questions from the CBR Indicators survey in Vietnam and the review of Simplican et al. [23]. We used a sum score of the social life base and supplementary indicators with the empowerment base indicators from the CBR Indicators, which covered the two major domains of social inclusion presented by Simplican et al.: interpersonal relationships (covered here by personal assistance, personal relationships, making decisions) and community participation (covered by feeling valued, participation in cultural and recreational activities, legal rights) [23]. Despite this coverage, the sum score of social inclusion used in our study has not been validated.

Furthermore, a wide range of variables which were not available from the collected data have been shown to have strong ties with social inclusion, such as social networks [5], housing, transportation problems, and fear of crime [16]. This limitation stems from the fact that the CBR Indicators were designed to collect data on personal characteristics and not environmental factors, though Bradshaw et al. found that environmental factors were less important than individual characteristics for social inclusion [16]. The CBR Indicators present the advantage of containing subjective responses, rather than just objective data, which is important as social inclusion is a personal experience, and reliance on objective data disregards personal experience [36]. The other advantage of using the CBR Indictors is that they cover the range of possible activities of CBR and therefore reflect potential targets that CBR programs can address.

The results of this study present valuable information for CBR programs and for other programs aiming to address the social inclusion of people with disabilities. Although people with disabilities face adversity in many aspects of life including health, education, livelihood, social life, and empowerment, this study found that empowerment and livelihood predictors were most strongly associated with social inclusion for CBR participants. Being able to make financial decisions was the greatest predictor of social inclusion for both CBR participants and the general population, showing the importance of livelihood, and also autonomy, when it comes to social inclusion. Although CBR programs are often health focused [33], CBR programs aiming to improve the social inclusion of people with disabilities should target empowerment and livelihood issues. Further research should aim to develop interventions and test their effectiveness at improving social inclusion.

Disclosure statement

No potential conflict of interest was reported by the authors.

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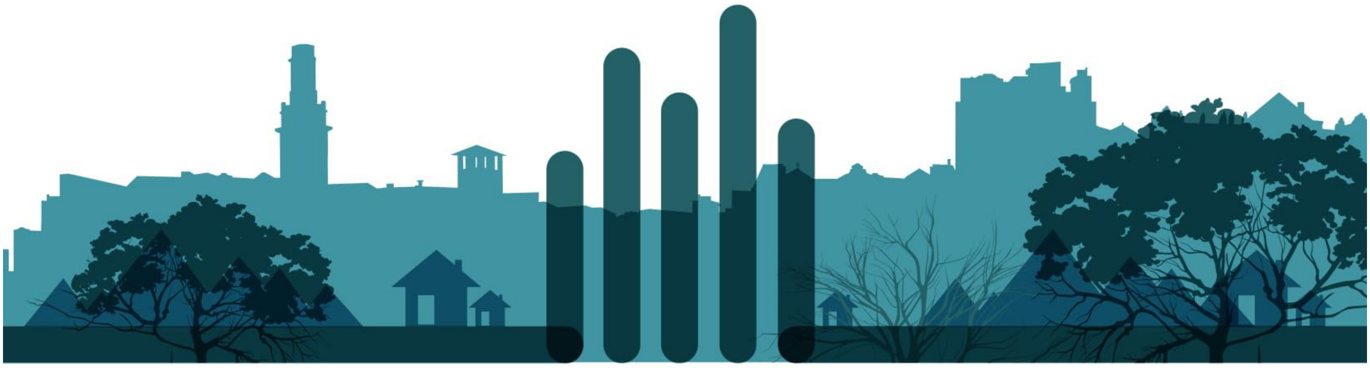
Capturing the difference we make

Community-based Rehabilitation Indicators Manual



World Health Organization

International Disability and Development Consortium

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ABBREVIATIONS

CBR	Community-based rehabilitation
CRPD	Convention on the rights of people with disability
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 disability while combating the perpetual cycle of poverty and disability. However, CBR has long lacked a strong evidence base, hindered in part by the absence of standardized indicators. This manual addresses these needs and responds to the call of the *WHO Global Disability Action Plan 2014–2021* to "strengthen collection of relevant and internationally comparable data on disability and support research on disability and related services".

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

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

INTRODUCTION

What is contained in this manual?

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

The purpose of CBR indicators

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

What is the added value of CBR indicators?

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

Collecting and using data

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

Who should use the CBR indicators and when?

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

Next steps

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

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

INDICATORS AT A GLANCE

GOALS OF THE INDICATORS

The indicators have two **goals**:

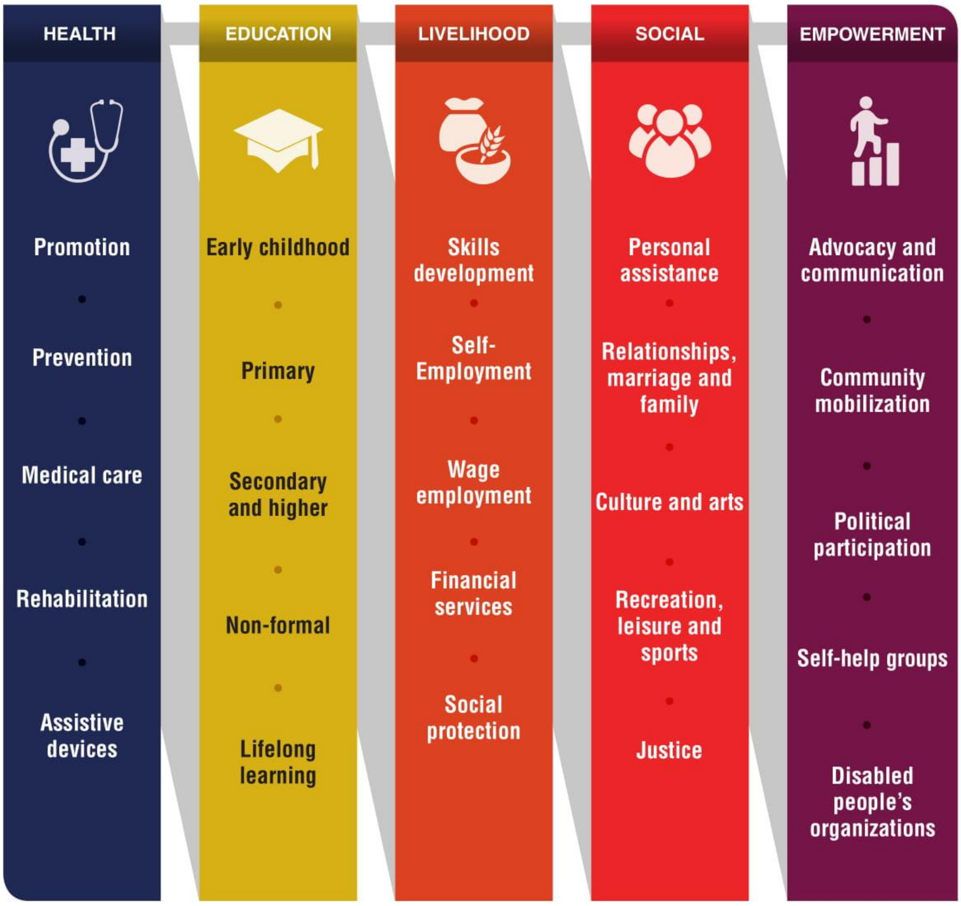
Capturing the situation of people with disability in the communities where CBR is implemented;

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

BASE AND SUPPLEMENTARY CBR INDICATORS

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

Figure 1. Components and elements of the CBR matrix



HEALTH	EDUCATION	LIVELIHOOD	SOCIAL	EMPOWERMENT
Promotion	Early childhood	Skills development	Personal assistance	Advocacy and communication
Prevention	Primary	Self-Employment	Relationships, marriage and family	Community mobilization
Medical care	Secondary and higher	Wage employment	Culture and arts	Political participation
Rehabilitation	Non-formal	Financial services	Recreation, leisure and sports	Self-help groups
Assistive devices	Lifelong learning	Social protection	Justice	Disabled people's organizations

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

	HEALTH	EDUCATION	LIVELIHOOD	SOCIAL	EMPOWERMENT
BASE INDICATORS	% of people with disability who: - 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	% of children with disability attending or completing primary education % of youth with disability attending or completing secondary education % of people with disability: - 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	% of people with disability who: - are self-employed or own-account workers - are working for wages or salary with an employer - have enough money to meet their needs	% of people with disability who feel valued as individuals by members of their community	% of people with disability who get to make informed choices and decisions
SUPPLEMENTARY INDICATORS	% of people with disability who: - 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	% of children with disability aged 36–59 months who are participating in early childhood education activities % of people with disability who use life-long learning opportunities to improve their life skills	% of people with disability who: - 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	% of people with disability who: - 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	% of people with disability who: - 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 disability with those without disability, except those pertaining to assistive devices, rehabilitation and disabled people's associations (DPOs).

This manual includes 40 base and supplementary indicators:

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

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

DATA TO INFORM CBR INDICATORS

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

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

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

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

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

SURVEY

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

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

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

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

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

CBR Indicators:
OVERVIEW OF DESIRABLE OUTCOMES, INDICATORS AND QUESTIONS

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

HEALTH

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

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

EDUCATION

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

EDUCATION

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

LIVELIHOOD

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

SOCIAL

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

EMPOWERMENT

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

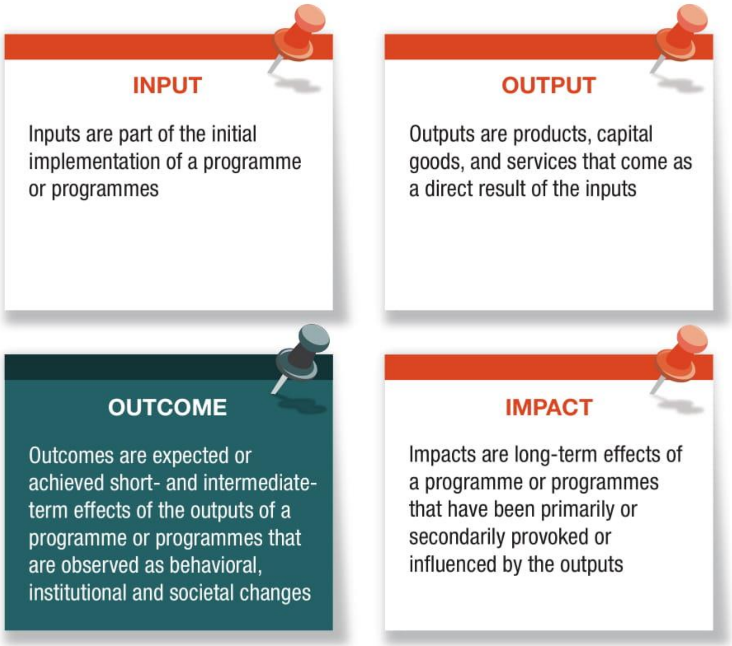
ANNEX 1:
CBR INDICATORS IN CONTEXT[1]

What is an Indicator?

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

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

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



INPUT

Inputs are part of the initial implementation of a programme or programmes

OUTPUT

Outputs are products, capital goods, and services that come as a direct result of the inputs

OUTCOME

Outcomes are expected or achieved short- and intermediate-term effects of the outputs of a programme or programmes that are observed as behavioral, institutional and societal changes

IMPACT

Impacts are long-term effects of a programme or programmes that have been primarily or secondarily provoked or influenced by the outputs

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

Outcome indicators were selected for two reasons:

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

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

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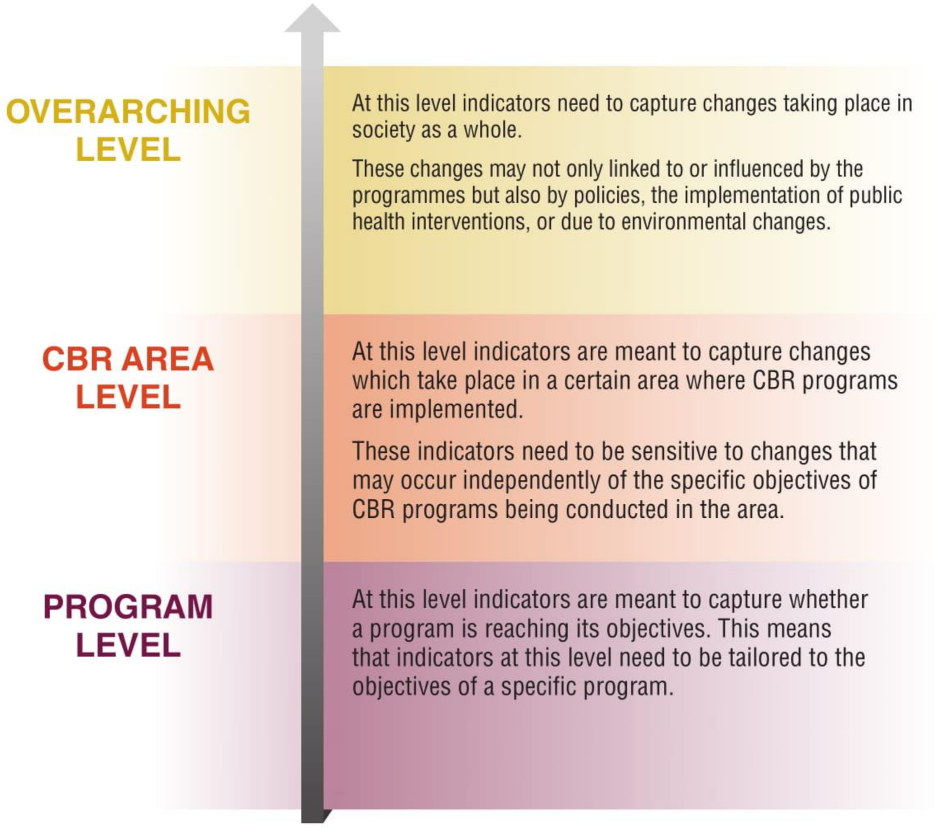
[1] This section is based on:
- Organisation for Economic Co-operation and Development. (2004). Glossary of Key Terms in Evaluation and Results Based Management. Paris: Organisation for Economic Co-operation and Development.
- Monitoring, evaluation and review of national health strategies: a country-led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

Levels of monitoring

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

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

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



OVERARCHING LEVEL

At this level indicators need to capture changes taking place in society as a whole.

These changes may not only linked to or influenced by the programmes but also by policies, the implementation of public health interventions, or due to environmental changes.

CBR AREA LEVEL

At this level indicators are meant to capture changes which take place in a certain area where CBR programs are implemented.

These indicators need to be sensitive to changes that may occur independently of the specific objectives of CBR programs being conducted in the area.

PROGRAM LEVEL

At this level indicators are meant to capture whether a program is reaching its objectives. This means that indicators at this level need to be tailored to the objectives of a specific program.

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

The indicators presented in this manual are designed to capture the difference CBR makes at the CBR area level rather than for specific CBR 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 10).

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/disability/cbr/guidelines/en/). However, since the desirable outcomes were originally not formulated to serve as the basis of indicators, they needed to be rephrased. This was done in an iterative process of several rounds between WHO and the IDDC CBR task force.

Phase three: Alpha-Version of CBR indicators

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

Phase four: Feasibility and validity testing

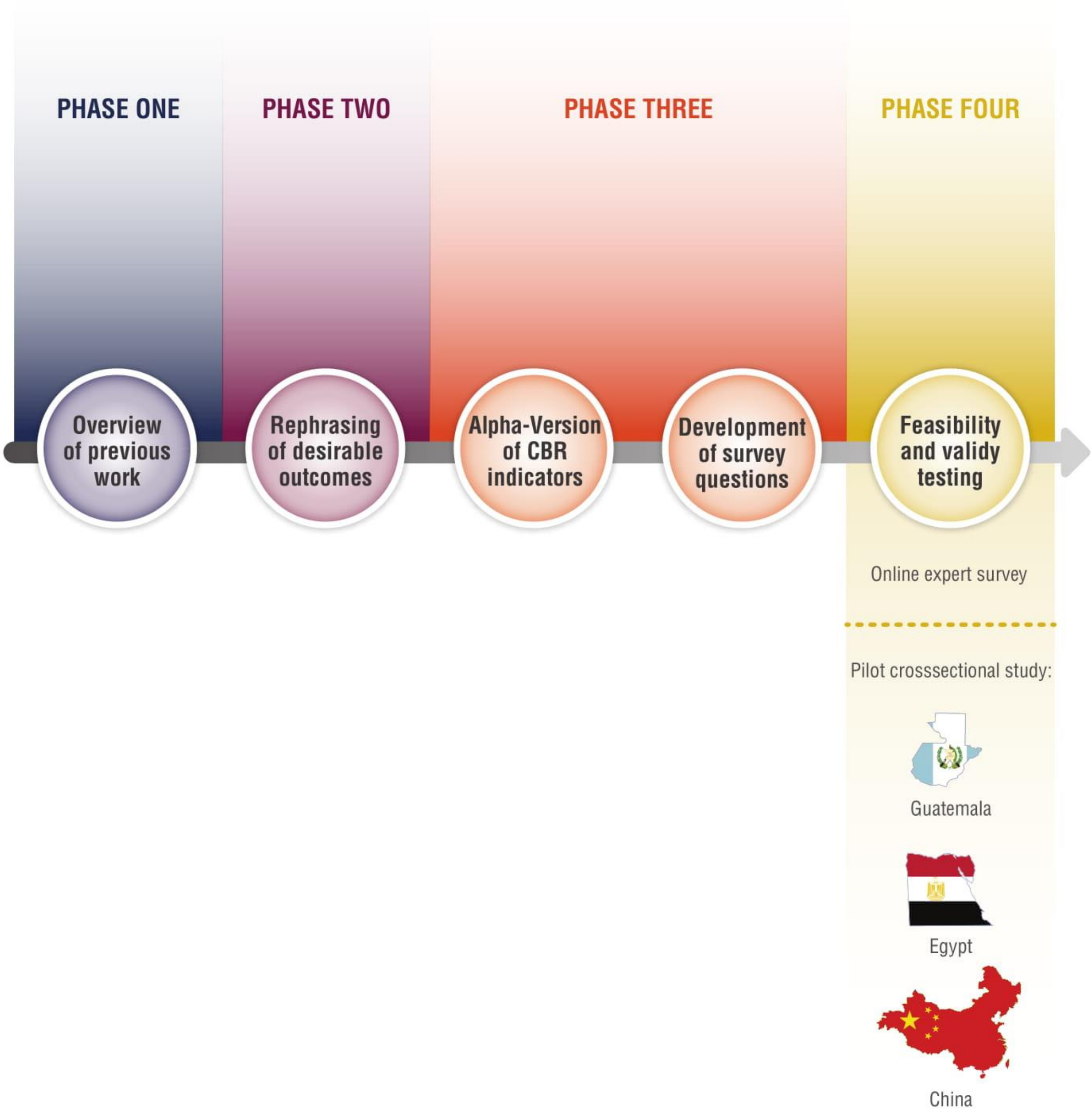
The feasibility and validity of the proposed indicators and questions were tested via two studies:

1) An **online expert** survey, in which CBR experts from varying backgrounds were requested to rank the indicators of each component and element by their relevance to CBR and to rate the face validity of the questions proposed to capture them.

2) A **pilot cross-sectional study** conducted in China, Egypt and Guatemala involving 801 participants with and without disability. The study was conducted using the questions proposed in Phase three and a first version of the Android app for data collection.

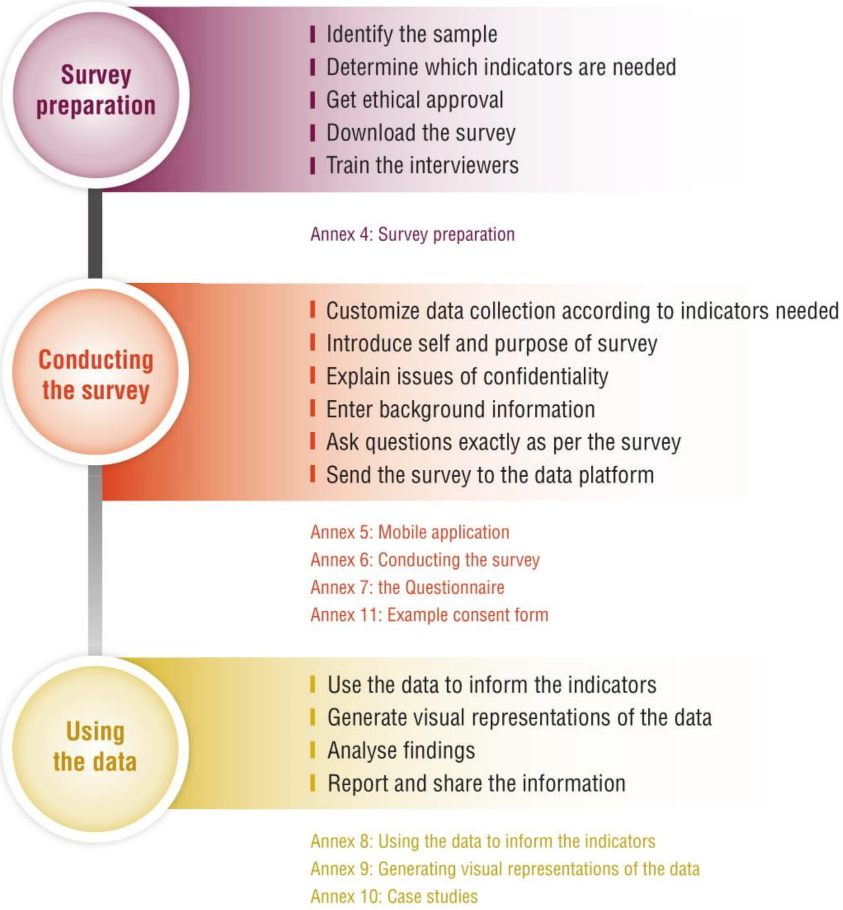
The compilation of results from 1) and 2) led to the selection of the set of **13 base** and **27 supplementary CBR indicators** that are presented in this manual.

Figure 5. Overview of the CBR Indicators Manual development process



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

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



Survey preparation

- Identify the sample
- Determine which indicators are needed
- Get ethical approval
- Download the survey
- Train the interviewers

Annex 4: Survey preparation

Conducting the survey

- Customize data collection according to indicators needed
- Introduce self and purpose of survey
- Explain issues of confidentiality
- Enter background information
- Ask questions exactly as per the survey
- Send the survey to the data platform

Annex 5: Mobile application
Annex 6: Conducting the survey
Annex 7: the Questionnaire
Annex 11: Example consent form

Using the data

- Use the data to inform the indicators
- Generate visual representations of the data
- Analyse findings
- Report and share the information

Annex 8: Using the data to inform the indicators
Annex 9: Generating visual representations of the data
Annex 10: Case studies

ANNEX 4:
SURVEY PREPARATION

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

INTERVIEWER GUIDE: SURVEY PREPARATION

Steps	What should be done
Identify the sample to be interviewed within the community where CBR is implemented	Two groups need to be approached for interviews: 1) Adults and children **with disability,**[2] regardless of whether they are currently participating in CBR or not. 2) Adults and children **without disability** living in the same community, so that a direct comparison between populations is possible. - In both groups, **a balanced sample** of men and women, boys and girls is recommended. - The groups of people with disability and people 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.
Determine which indicators are needed	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. - 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.
Get ethical approval for conducting the survey	Ensure ethical approval is acquired according to the regulations of the country, region or institution.

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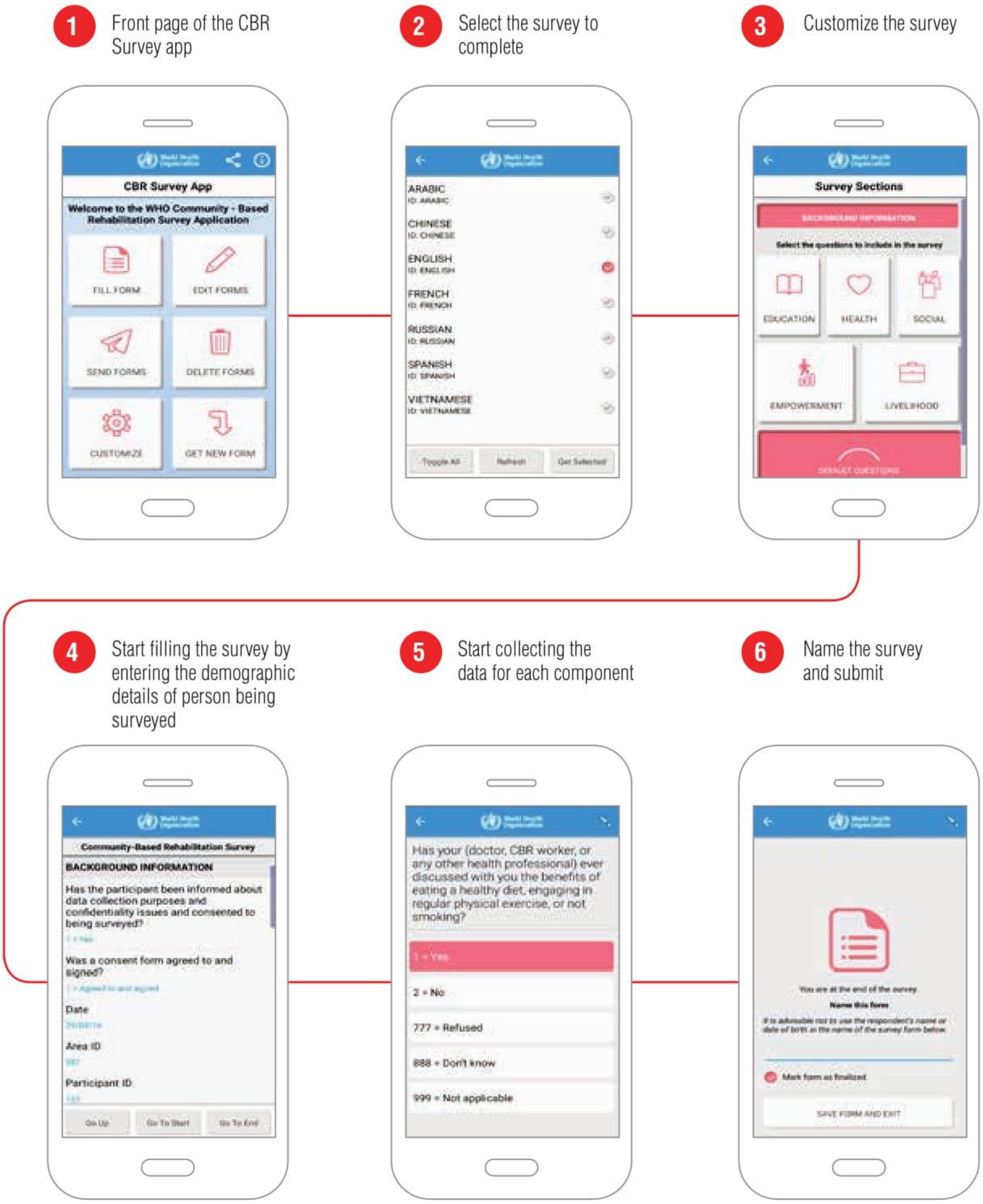
[2] The ICF definition of disability that was used in the WHO World report on disability should be used to determine who is classified as an adult or child with a disability: Disability is an umbrella term for impairments, activity limitations, and participation restrictions, and represents the outcome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

ANNEX 4:
SURVEY PREPARATION CONT

SURVEY PREPARATION	
Steps	**What should be done**
Confidentiality and mechanisms for follow up	**All data must be collected anonymously using a participant ID.** **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'). When repeating the survey, ensure that the same participant numbers are re-entered so the data can be linked.
Download the mobile app or hard-copy of the survey	An intuitive and easy to use **Android app for mobile** phones has been developed to collect data with the questions outlined in this manual. **The mobile app…** **…can be downloaded** via the WHO CBR website (http://www.who.int/disability/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 an email address of your choice or WHO's Data Collection Platform. Alternatively, **a hard-copy version of the survey** is available on the WHO CBR website (http://www.who.int/disability/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.
Train the interviewers	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. Issues of confidentiality and informed consent should be well understood by all interviewers.
Automatically reviewing submitted data	- 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 people with disability with other members of the community, as well as comparing boys, girls, men and women.
Customize data collection	- 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.
Introduce oneself and the reason for the interview	A recommended introduction is: *"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."*

ANNEX 5:
MOBILE APPLICATION

Figure 7. Using the mobile application



1. Front page of the CBR Survey app
2. Select the survey to complete
3. Customize the survey
4. Start filling the survey by entering the demographic details of person being surveyed
5. Start collecting the data for each component
6. Name the survey and submit

CBR Survey App

Welcome to the WHO Community - Based Rehabilitation Survey Application

Survey Sections

Select the questions to include in the survey

Community-Based Rehabilitation Survey

BACKGROUND INFORMATION

Has the participant been informed about data collection purposes and confidentiality issues and consented to being surveyed?

1 = Yes

Was a consent form agreed to and signed?

1 = Agreed to and signed

Date

[illegible]

Area ID

[illegible]

Participant ID

[illegible]

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

777 = Refused

888 = Don't know

999 = Not applicable

You are at the end of the survey.

Name this form

It is advisable not to use the respondent's name or date of birth as the name of the survey form below.

● Mark form as finalized

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

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

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

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

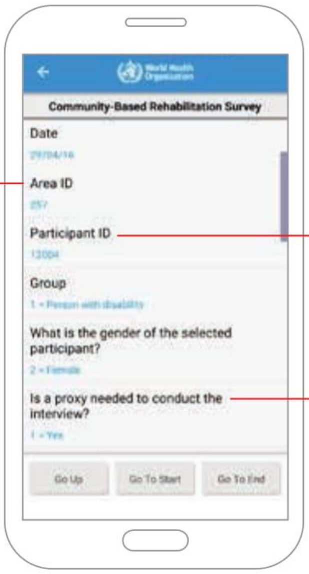
Data is entered anonymously and temporarily stored on the mobile phone until it is submitted, at which time it will be sent to the user or stored on the WHO Data Collection Platform (https://beta.whodcp.org).

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

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

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

Figure 8. Explanation of background information



Community-Based Rehabilitation Survey

Date

29/04/16

Area ID

257

Participant ID

12004

Group

1 = Person with disability

What is the gender of the selected participant?

2 = Female

Is a proxy needed to conduct the interview?

1 = Yes

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.

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 6:
CONDUCTING THE SURVEY

THE INTERVIEW	
Steps	**What should be done**
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 *"Has the participant been informed about data collection purposes and confidentiality issues and consented to being surveyed?* Yes/No. If the answer is yes, the interviewer will be prompted by the app, *"Was a consent form agreed to and signed?"* If a consent form is not needed, select Not Applicable. An example of a consent form that may be used when conducting the survey can be found in Annex 11.
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 disability, 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.
Decide whether a proxy is needed to conduct the interview	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. 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.
Record the participant's age	Enter the participant's age in the Background page of the app.

ANNEX 6:
CONDUCTING THE SURVEY CONT.

THE INTERVIEWER	
Steps	**What should be done**
Probe if respondent has difficulties answering	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: - misinterprets or does not understand the question - cannot make up his or her mind, or - says that they don't know the answer. **Probing techniques include to:** **Repeat the question** – The respondent may come up with the answer if they hear the question a second time. **Pause** – This gives the respondent time to collect their thoughts. **Repeat the respondent's reply** – This is often an effective way of having the respondent reflect on the answer they have just given. **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…?"
If probing does not lead to an answer, use the "Not applicable", "Don't know" or "Refuse" response options as appropriate	**"Not applicable"** – Some questions may not apply or be relevant for the respondent. In this case, select this option. **"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. **"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.

ANNEX 7:
THE QUESTIONNAIRE

Boxes shaded in grey denote those that inform base indicators.

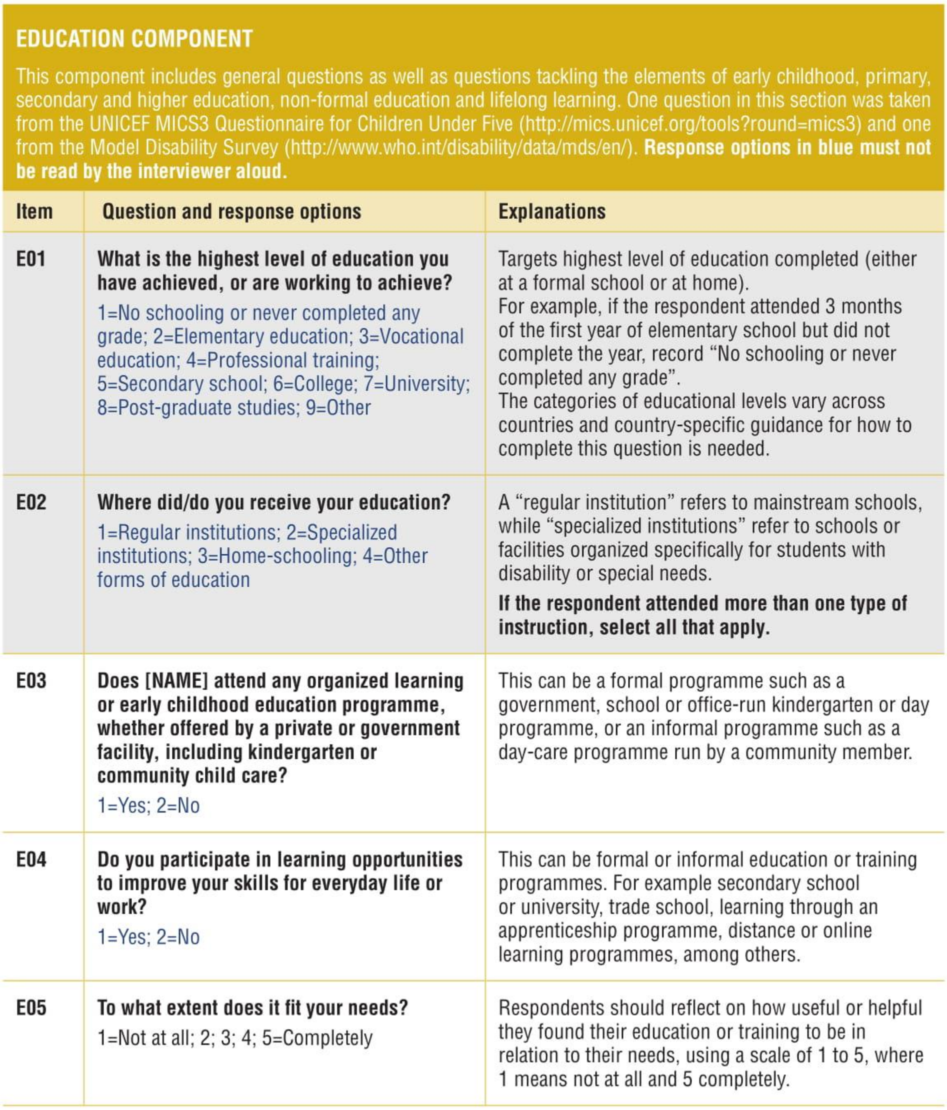
HEALTH COMPONENT

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/disability/data/mds/en/) and from the GALLUP Annual Consumption Habits Poll (http://www.gallup.com/poll/163772/americans-say-doctors-advise-health-habits.aspx). **Response options in blue must not be read aloud by the interviewer**

Item	Question and response options	Explanations
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, I was unable to get the care I needed 2=No, I got the care I needed No; 3=No need for health care in the past 12 months	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 twhat 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.

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

Item	Question and response options	Explanations
H07	**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, I was unable to get the services I needed 2=No, I got the services I needed 3=No need for rehabilitation services in the past 12 months	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 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	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.
H11	**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	Visual aids are, for instance, glasses or books with large print, a white cane or guide dogs, among others.
H12	**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	Hearing or communication aids are, for instance, usual hearing devices, a visual or vibrating alarm, a cochlear implant or a voice amplifier, among others.
H13	**Do you know how to keep your assistive device in good working condition?** 1=Yes; 2=No; 3=Not applicable	This refers to the respondent either being able to repair or maintain the assistive device themselves so it works as it should, or knowing someone who can repair or maintain it for them.



EDUCATION COMPONENT

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

Item	Question and response options	Explanations
E01	**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	Targets highest level of education completed (either at a formal school or at home). For example, if the respondent attended 3 months of the first year of elementary school but did not complete the year, record "No schooling or never completed any grade". The categories of educational levels vary across countries and country-specific guidance for how to complete this question is needed.
E02	**Where did/do you receive your education?** 1=Regular institutions; 2=Specialized institutions; 3=Home-schooling; 4=Other forms of education	A "regular institution" refers to mainstream schools, while "specialized institutions" refer to schools or facilities organized specifically for students with disability or special needs. **If the respondent attended more than one type of instruction, select all that apply.**
E03	**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?** 1=Yes; 2=No	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.
E04	**Do you participate in learning opportunities to improve your skills for everyday life or work?** 1=Yes; 2=No	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.
E05	**To what extent does it fit your needs?** 1=Not at all; 2; 3; 4; 5=Completely	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.

LIVELIHOOD COMPONENT

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

Item	Question and response options	Explanations
L01	**What is your current working situation?** 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	Respondents should think of their current working situation. If their response does not match an option, select "Other".
L02	**Do you have enough money to meet your needs?** 1=Not at all; 2; 3; 4; 5=Completely	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.
L03	**Do you get to decide how to use your money?** 1=Not at all; 2; 3; 4; 5=Completely	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.
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/disability/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
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.
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/whoqolbref/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 disability 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 8:
USING DATA TO CALCULATE INDICATORS

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

Indicator

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

Question

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

Answer: Yes or No

Step 1. Collect the data using the survey question

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

134 people with disability (56 women and 78 men)

153 people without disability (81 women and 72 men)

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

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

With disability			Without disability		
	Yes	No		Yes	No
Men (78)	30	48	Men (72)	59	13
Women (56)	16	40	Women (81)	65	16
Total	**46**	**88**	**Total**	**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 disability, all people without disability, or the total number of men or women in either category depending on what group you wish to look at). **'Part'** is the number of men or women (or both) with or without disability who answered "yes" (because this indicator shows how many people do know). For example, to calculate the percentage of **women with and without disability that answered "Yes"** (the 'part'= 16 and 65 respectively), the whole would be the complete number of women with disability (56) and all women without disability (81). The formula would therefore be used as follows:

Women with disability

$$\frac{16}{56} \text{ x100} = 28.6\%$$

Women without disability

$$\frac{65}{81} \text{ x100} = 80.2\%$$

The indicator would therefore be:

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

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

People with disability

$$\frac{46}{134} \text{ x100} = 34.3\%$$

People without disability

$$\frac{124}{153} \text{ x100} = 81\%$$

The indicator would therefore be:

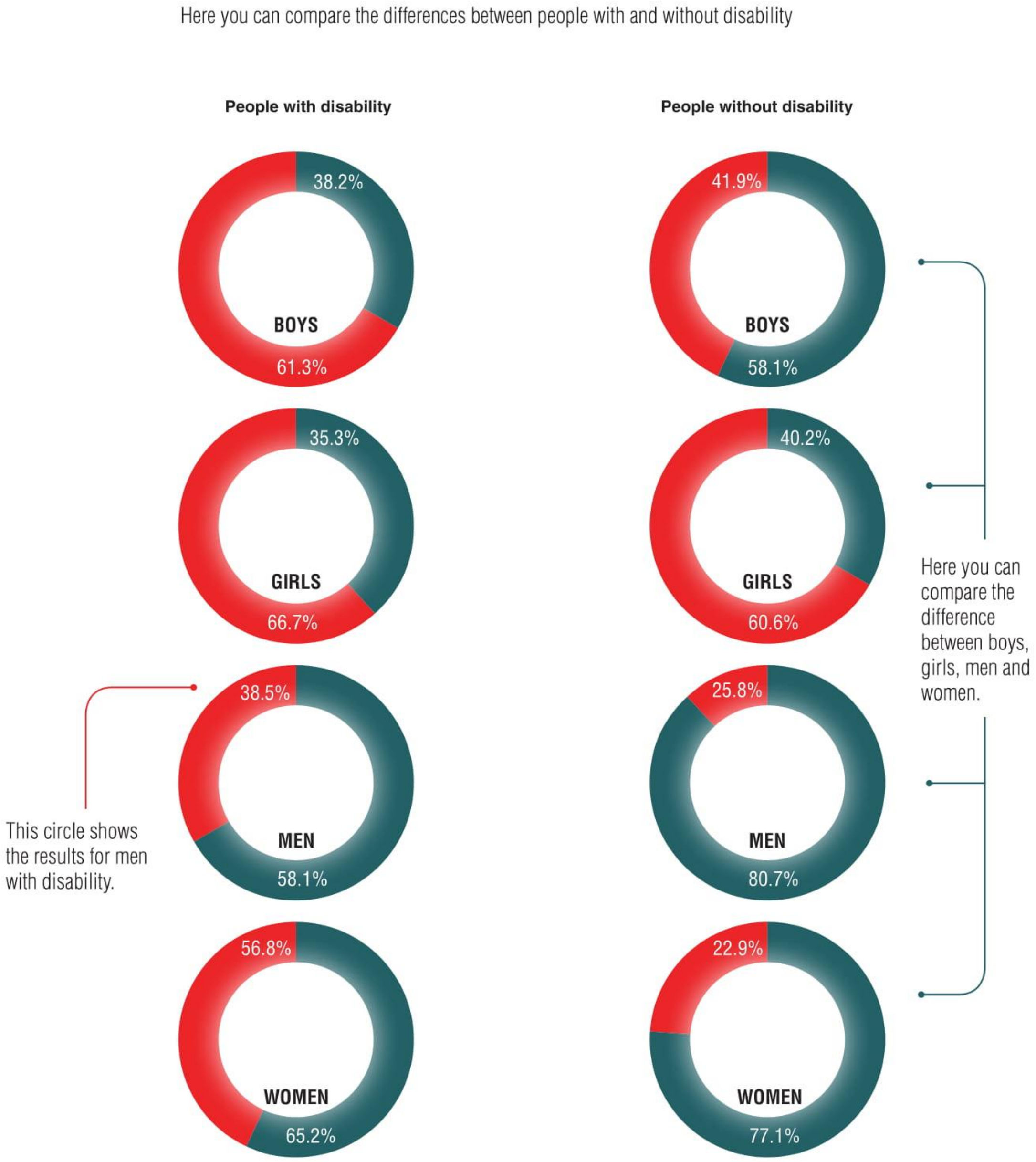
34.3% of people with disability know that physical activity and eating habits influence their health compared to 81% of people without a disability.

ANNEX 9:
GENERATING VISUAL REPRESENTATIONS OF DATA

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

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

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



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

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

ANNEX 10:
CASE STUDIES

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

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

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

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

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

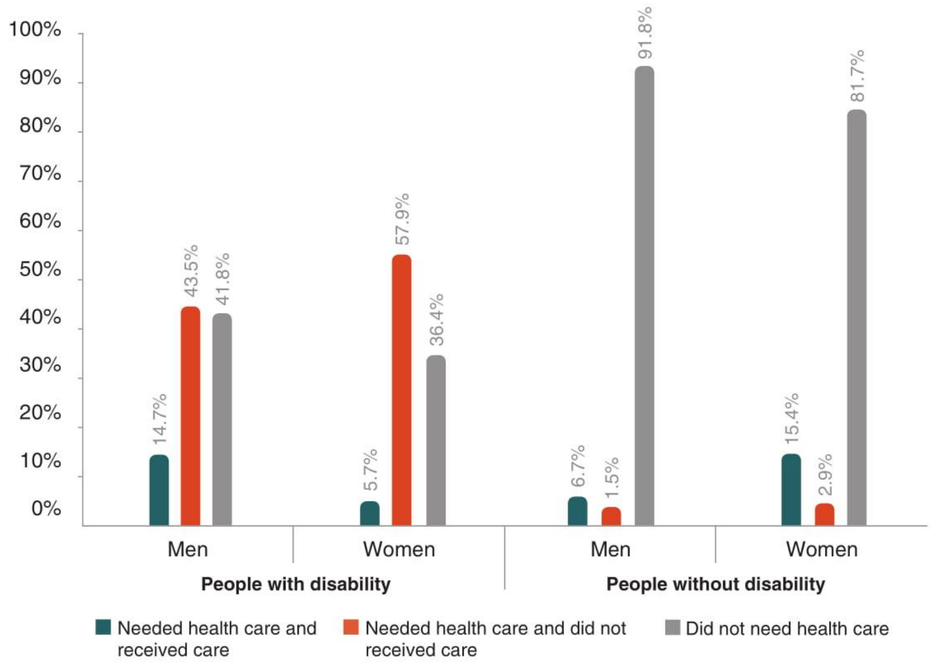
The results showed that people with disability in the town have significantly less access to medical care than people without disability (Graph 1). This strongly supported the assumption prior to data collection that people with disability in the area face barriers in accessing medication. Additionally,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

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

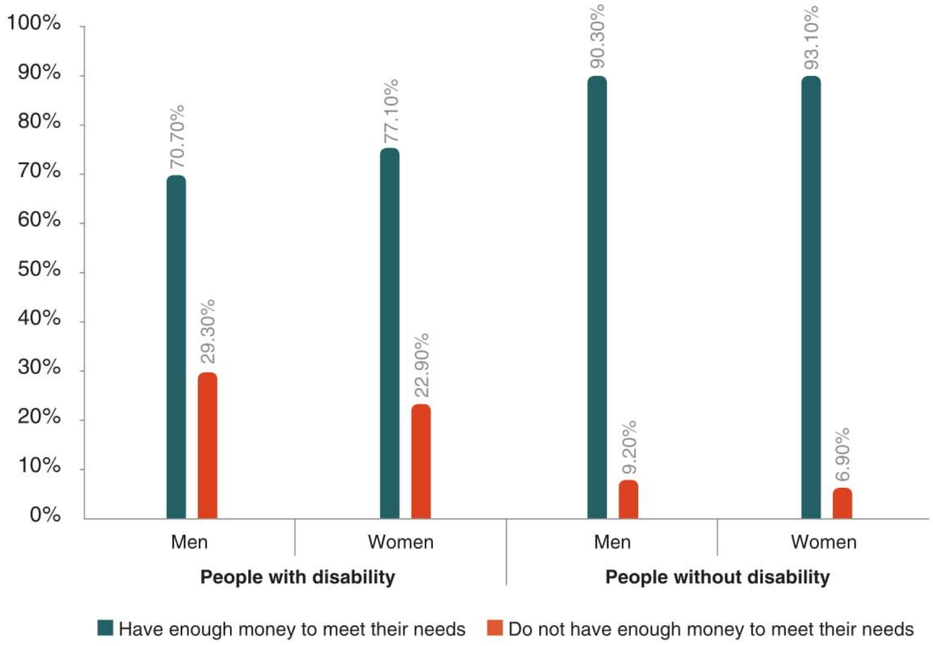
Meanwhile, the Rehabilitation Officer, together with the CBR workers, prepared a stakeholder meeting with people with disability, local DPOs, social workers and a representative of the local Chamber of Commerce to gather ideas about how people with disability and their family members can have better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

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

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



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



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

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

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

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

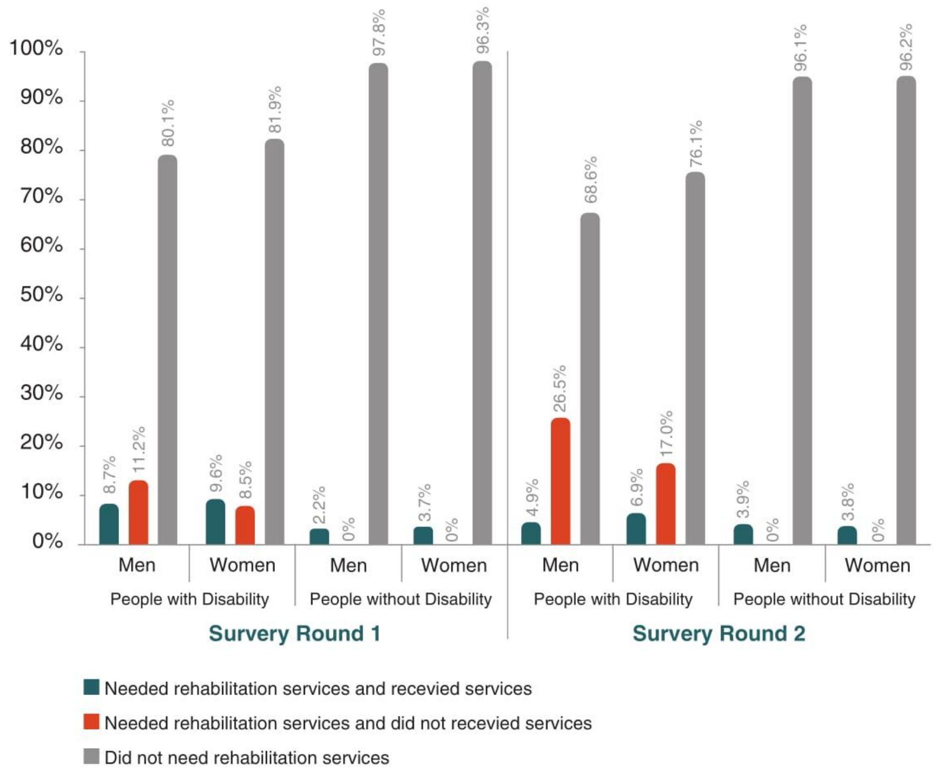
The municipal assembly advised further CBR implementation in coordination with primary health services, the local labor office and mainstream nongovernmental organizations (NGOs) working in income generation. A subsequent meeting with these stakeholders included a more in-depth analysis of the baseline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

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

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

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

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



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

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

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

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

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

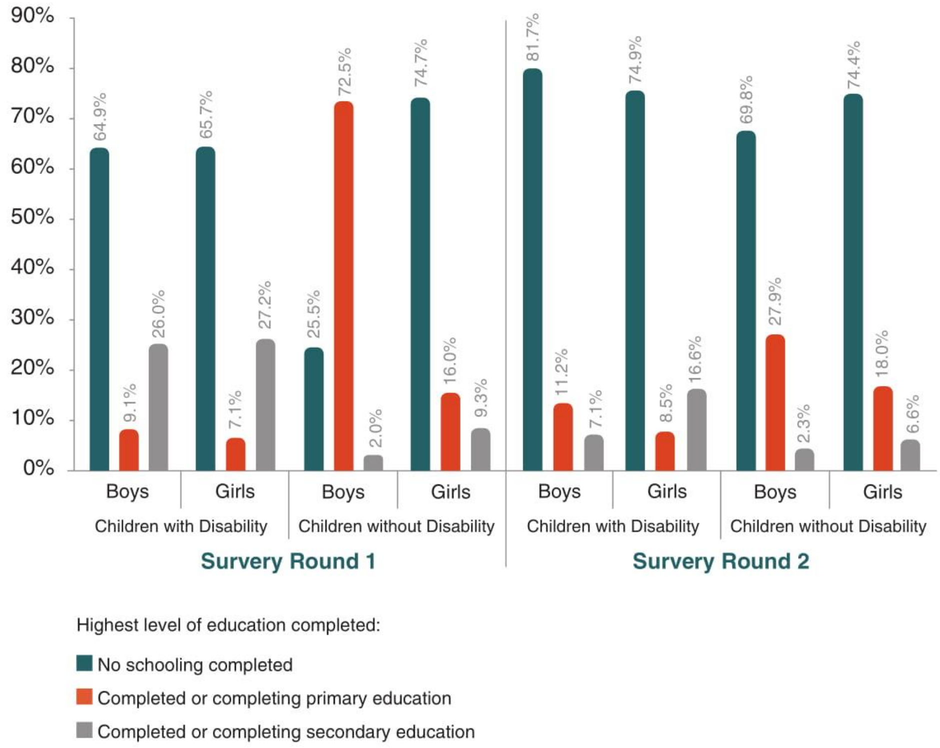
One year later the survey was repeated to check up on the changes in the community. The results showed an improvement in school enrolment but no significant improvement in health status (Graphs 1 and 2).

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

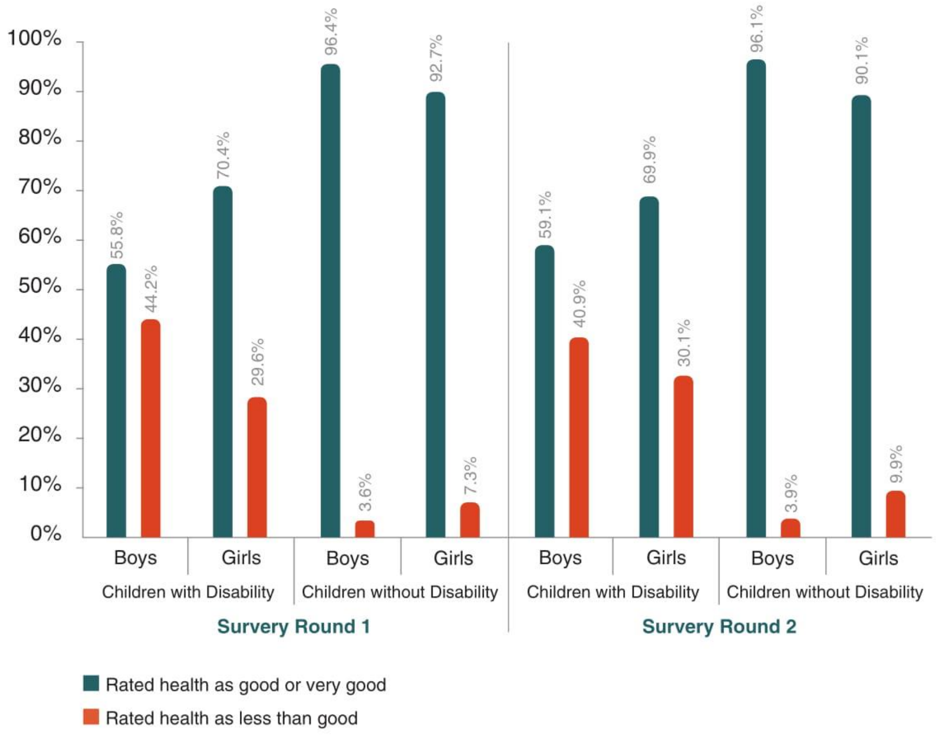
Subsequently the CBR manager organized a stakeholder meeting with school headmasters, local school authorities and representatives of parent-teacher associations to discuss these results and identify the barriers to school inclusion. They found the main hindering factors to be physical access to classrooms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

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

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



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



ANNEX 11:
EXAMPLE CONSENT FORM

Dear participant,

Selection	You have been selected to be part of this survey and this is why we would like to interview you. This survey is conducted by the [enter name of organization, institution or government body] and will be carried out by interviewers from [name of place interviewers have been selected from]. This survey is currently taking place in several areas around the world.
Confidentiality	The information you provide is totally confidential and will not be disclosed to anyone. It will only be used for the purposes of showing the difference between people with disability and people without disability in this area. Only a code will be used to connect your name and your answers without identifying you.
Voluntary participation	Your participation is voluntary and you can withdraw from the survey after having agreed to participate. You are free to refuse to answer any question that is asked in the questionnaire. If you have any questions about this survey you may ask me or contact [name of person, organization or government body to contact] or [Principal Investigator at site].
Consent to participate	Signing this consent indicates that you understand what will be expected of you and are willing to participate in this survey.

Read by participant		**Interviewer**	
Agreed		**Refused**	

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

Name:	**Sign:**

Parent/Guardian:	**Sign:**

ANNEX 12:
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 disability. CBR is implemented through the combined efforts of people with disability themselves, their families, organizations, and communities, and the relevant governmental and nongovernmental health, education, vocational, social, and other services.[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 people 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 disability 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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