

Evaluating the Impact of Rehabilitation in the Lives of People with Disabilities and their Families in Low and Middle Income Countries A Review of Tools

August 2010

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CBM, Germany



Purpose of report

This report has been commissioned by CBM, an international disability organisation working with local partners around the globe to improve the quality of life of the world's persons with disabilities who live in the most disadvantaged societies. CBM is increasingly interested in evidencing and evaluating the extent to which they are achieving this goal, so that they can plan and implement their programmes in the most cost-effective way. As there are many tools available for evaluating impact in the international literature, CBM commissioned this review in order to obtain clear guidance on how research can be carried across their programmes in order to generate high quality and reliable evidence on the impact of their programmes in the lives of people with disabilities and their families.

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ABBREVIATIONS

| | |
|--------|---|
| A&P | Activities & Participation |
| ADL | Activities of Daily Living |
| AWDs | Adults with Disabilities |
| CBA | Cost-Benefit Analysis |
| CEA | Cost-Effectiveness Analysis |
| CCOs | Client-Centred Outcomes |
| CROs | Client-Reported Outcomes |
| CS | Case Series |
| CUA | Cost-Utility Analysis |
| CWDs | Children with Disabilities |
| HRQOL | Health-related quality-of-life |
| ICF | International Classification of Functioning Disability & Health |
| ICF-CY | ICF-Children & Youth version |
| LMICs | Low and Middle Income Countries |
| M&E | Monitoring & Evaluation |
| MOS | Medical Outcomes Study |
| PRO | Patient (or Proxy)- Reported Outcomes |
| PWDs | People with Disabilities |
| QALYS | Quality-Adjusted Life Years |
| QOL | Quality-of-life |
| RCT | Randomised Controlled Trial |
| UV | Utility Value |
| WHO | World Health Organisation |
| WHODAS | WHO Disability Assessment Schedule |
| WHOQOL | WHO Quality-of-Life instrument |

1. INTRODUCTION

1.1. People with Disabilities (PWDs)

Disability can be understood as "*the outcome of the interaction between a person with an impairment and the environmental and attitudinal barriers he or she may face*"¹. This interaction can lead to a person being limited in doing activities and restricted in participating in society at large. This is the model of disablement defined by the World Health Organisation's (WHO) International Classification of Functioning, Disability and Health (ICF).¹⁻²

It is estimated that there are 600 million people with disabilities globally. The vast majority (80%) live in low and middle income countries (LMICs), and disability is believed to affect disproportionately the most disadvantaged sector of the population.³⁻⁴

Moreover, restricted participation in education and employment for people with disability (PWD) living in LMICs can further exacerbate their poverty.⁴ The high proportion of PWDs in the world (10%) makes it very unlikely that the Millennium Development Goals can be achieved without mainstreaming disability into development initiatives. As the former president of the World Bank, James Wolfensohn, has said:

"Unless disabled people are brought into the development mainstream, it will be impossible to cut poverty in half by 2015 or to give every girl and boy the chance to achieve a primary education by the same date - goals agreed to by more than 180 world leaders at the United Nations Millennium Summit in September 2000."

1.2. Rehabilitation services and CBM

The UN Convention on the Rights of Persons with Disabilities⁵⁻⁶ states that **comprehensive rehabilitation** services involving different types of interventions – including medical and social - are needed to ensure the equal rights and participation of PWDs in societies:

'States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services...' (Article 26)

However, only 2% of PWDs in LMICs have access to basic healthcare and rehabilitation services, let alone comprehensive services.⁴ As a consequence, the

vast majority do not lead lives consonant with the spirit and values embodied in the United Nation's Convention on the Rights of People with Disabilities.

CBM is working to close this gap by developing and delivering effective and comprehensive rehabilitation services to PWDs in LMICs. The purpose of CBM's work is to **improve the quality of life of PWDS** living in the poorest most disadvantaged societies in the world. This is done by working with local partner organisations to support the availability and accessibility of healthcare, rehabilitative, educational and livelihood generation services for adults and children with disabilities in LMICS. CBM has over 730 partners in over 80 countries, most of which are in Africa, Asia and Latin America.

While rehabilitation services have mostly been developed for people with a single category of impairment (e.g. blindness) to the exclusion of others (e.g. hearing) in the past, CBM are now promoting a **comprehensive approach to all categories of disability** among their projects, particularly those that are community-based (CBM Policy Paper on Community Based Rehabilitation - CBR). This movement from a 'single and exclusive' to a 'multiple and inclusive' approach means working with all types of disability, all ages, and all forms of intervention.

1.3. The impact of rehabilitation services in the lives of PWDs

Development agencies aim to make a **real and positive impact** in people's lives. Providing evidence of activities undertaken (e.g. numbers of surgeries performed, clients attending) or clinical outcomes (e.g. healing, visual acuity) fulfils some aspects of accountability. However, these data alone do not provide assurance that the intervention delivered has resulted in a real improvement in the lives of the clients and their families as intended. It is now well accepted that having an impairment does not necessarily lead to the experience of poor quality of life and/or disability (activity limitations and restrictions in participation). Likewise, there is no reason to assume that treating the impairment or changing the environment will necessarily lead to an improvement in wellbeing. It is therefore important to assess the impact that services have in the lives of PWD.

Impact is defined as the '*Positive and negative, primary and secondary long-term effects produced by a development intervention, directly or indirectly, intended or unintended*' (Development Assistance Committee). Thus impact assessments aim to assess the following questions:

- Has a programme/service/intervention achieved its basic aim?
- What real difference did this programme/service/intervention make?
- Are observed changes a result of the programme? (i.e. establishing causality, attribution)

The purpose of **Impact Assessment** in the field of disability and rehabilitation is to create a critical mass of data to evidence the effectiveness of rehabilitative services in improving the lives of PWDs in real terms. This information can be used to

inform rehabilitation policy and practice, and set benchmarks for rehabilitation services that are comparable across programmes and interventions.

There is a lack of evidence for the impact of interventions across development programmes and those studies that are done '*frequently fail to yield useful information because they do not use rigorous methods or data*'.⁷ For example, a review of the evidence base for CBR in 2005 reported that studies evaluating CBR are mostly descriptive and theoretical; very few actually test the effectiveness of interventions.⁸ There is therefore a need for development agencies to start to undertake high quality research to evidence the impact of their programmes using robust methods. This review of research methods and tools for impact evaluations is a step in that direction.

1.4. Methodological Aspects of Impact Evaluations

1.4.1. Impact Evaluations v. Monitoring & Evaluation

In this review, we refer to impact evaluations as discrete studies that may be undertaken separately, or in parallel, to routine monitoring and evaluation (M&E) activities in a programme. Of course there is overlap between impact evaluation and M&E. Impact assessments primarily aim to evidence and measure the **outcomes** of a programme/service/intervention in the lives of the individuals and their families, and sometimes the wider community. Importantly, impact evaluations are primarily concerned with attributing causes to outcomes. Results may be generalisable to wider contexts and may have important implications for policy and practice.

By contrast, M&E is '*A continuing function that uses systematic collection of data on specified indicators to provide management and the main stakeholders of an ongoing development intervention with indications of the extent of progress and achievement of objectives and progress in the use of allocated funds*' (Development Assistance Committee). In other words, M&E primarily aims to inform whether and how a programme is meeting its objectives for the purpose of ongoing management and accountability. Data on both the **processes** and **outcome** of an intervention are collected routinely using a management information system. The results are primarily for internal use and are less likely to be generalisable.

There is growing literature on frameworks, classification models, and indicators for the comprehensive evaluation of rehabilitation, specifically CBR.⁸⁻¹² Comprehensive evaluations using M&E might evaluate the impact of a programme on PWDs and their families, but also the impact of the programme and training in the staff and community, staff performance, income/expenditure, and the quality of services.⁹ This review is concerned with providing robust evidence on the first component (the impact in the lives of PWDs and their families) through in-depth impact evaluations.

1.4.2. Quantitative and Qualitative Data Collection

A mixture of both quantitative and qualitative methods is needed for comprehensive impact evaluations:

- **Quantitative** methods are needed to objectively **measure** the change in outcomes that have arisen as a result of an intervention so that one knows just how much a client's situation has improved.
- **Qualitative** methods are useful at various stages of the evaluation to assess what clients perceive to be the benefits and detriments associated with the intervention. For example, qualitative data collection may be used at the start of the project to **identify** important variables that need to be collected for comprehensive statistical analyses and to **develop the content or adapt** quantitative questionnaires. Later in the study, qualitative data may be collected to **explain** the results observed from an impact evaluation, and to **explore** ways of integrating results into future planning and implementation. By the very nature of text-based data, there are no standardised 'off the shelf' tools for collecting and analysing qualitative data across different types of disability or interventions, and so they are not considered in this review.

More comprehensive qualitative evaluations may provide valuable descriptions of the practice, strategies and outcomes that can be used to guide policy and practice¹³.

1.4.3. Client-Centred Outcomes and Tools

Client-Centred Outcomes (CCOs)

Making an 'impact' is about making a real and tangible difference in the lives of PWDs and their families - from their perspective. The ultimate unit of outcome must therefore be PWDs and their families, and the outcomes that are measured must include those that are viewed as important to them.

A visually impaired person is not interested in whether his or her vision is 6/18 or 6/30 (a clinical measure of visual acuity), but whether s/he can do the things desired, and has a good quality-of-life (QOL). Moreover, measurement of changes in vision in the clinical setting cannot be assumed to translate into tangible, perceivable improvements in the lives of the clients. It is therefore not enough to measure clinical outcomes only and assume that they translate into better QOL.

In this report we refer to 'client-centred outcomes' as those that are important in the lives of PWDs and their families who access rehabilitation services. These include:

- Functioning, Activities and Participation (Disability)
- Quality-of-Life (and Health-related quality-of-life)
- Health Status
- Poverty

Functioning, Activities and Participation is best defined by the ICF,¹⁻² where **functioning** is the 'physiologic functions of the body systems' including those that are psychological, **activity** is the 'execution of a task or action by an individual' (e.g. standing, lifting, eating), and **participation** is the involvement of an individual in a life situation (e.g. employment, education). Different categories of Activities and Participation are combined in the ICF.

QOL assesses the general wellbeing of an individual while health is defined as 'a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity' (WHO definition).

The above CCOs are therefore multidimensional concepts that include physical, psychological and social dimensions. Because of the overlap between concepts such as Activities/Participation/Health Status/QOL/HRQOL/wellbeing, the terms are often used interchangeably. Changes in different dimensions of each concept (e.g. physical versus emotional functioning) can be measured in impact evaluations, giving valuable descriptive evidence on *how* outcomes (e.g. QOL) have improved following intervention?

Tools used to measure CCOs

CCOs can be quantitatively measured, just like clinical outcomes. CCOs may be measured objectively (e.g. assessments of household income to measure poverty) or subjectively (e.g. self-reported poverty or self-reported quality of life). The tools used to collect data on CCOs for impact evaluations are largely questionnaires with standardised content and response options, so that data can be compared within and between groups.

CCOs are mainly obtained through self-report from the individual. In the medical arena, self-reported measures of concepts such as health status and QOL are called Patient-Reported Outcomes (PRO). This is an umbrella term that applies to all concepts reported by the patient or a close proxy. In rehabilitation, it is more relevant to use the term 'client-reported outcome' (CRO).

For populations who are unlikely to give reliable self-reports (e.g. young children; people with cognitive impairments), proxies of close family members and guardians are often used as reporters because of their close familiarity with the client's everyday life. Children as young as 5 have been evidenced to reliably report on their quality of life,¹⁴⁻¹⁵ however in contexts of low literacy and access to education, it may be inappropriate to elicit data from children younger than 8 or 10 years old. Moreover, it has been shown that children and parents frequently do not agree when reporting on child-centred outcomes, particularly those that are invisible to the eye (e.g. emotional health v. physical activities)¹⁶. Therefore if interventions are assessed for children across a wide age span (e.g. 4-16 yrs), it is advisable to elicit a consistent perspective (i.e. parent) or both the parent and child if feasible.

Tools measuring CCOs can be either single-item tools or multi-item scales. Single-item measures use a single question, reported by the client/proxy, to measure the concept of interest (e.g. How would you rate your overall QOL?). Single-item measures are, however, not recommended as the primary outcomes in impact evaluations because it is unlikely that they can effectively capture a given phenomenon and it is difficult to assess the adequacy of a single-item instrument both conceptually and statistically.

A more robust way of measuring CCOs is by using multi-item scales that use a series of self-report questions to measure the same concept. The question responses can be combined to provide a summary score that represents the concept of interest and is suitable for statistical calculations. Lengthier questionnaires, however, pose a time and cost burden on both the respondent and researcher.

It is important to consider the concept and content validity of the tools. Many CRO tools have been developed internationally, however the vast majority originate from high-income countries in North America/Europe, and are based on what matters to populations of 'Western' culture (e.g. driving, TV watching). Simply translating a questionnaire from e.g. UK (English) to Kenya (Swahili) will not produce a tool that is conceptually equivalent or even relevant in a LMIC in Africa, Asia or Latin America.¹⁷ To ensure that the concepts the questions of a tool are valid to people in LMICs, it is better to develop the concepts and content empirically in the local population through interviews and focus groups. If an existing tool is adapted to a new population and culture it must be shown to be conceptually valid,¹⁷ and there are international guidelines for doing this assessment.¹⁸⁻²¹

1.4.4. Design of Impact Evaluations

Below are some key components that should ideally be incorporated into the design of impact evaluations, in addition to the use of standardised tools to measure impact:

- **Measurement of outcomes before and after the intervention** has been given. This is needed to measure the change in outcomes (e.g. quality of life) that has been brought about by an intervention and requires a **prospective** (longitudinal) research design, where data is collected at **2 time points**. Some studies attempt to measure change retrospectively at follow-up only (using a cross-sectional design) by asking clients to remember what their life was like previous to the intervention compared to now, or comparing clients who have received an intervention to those who have not. This is not advised unless it is unavoidable (e.g. contexts where research cannot be planned in advance of interventions delivered, such as conflicts and disasters),²² as client's are many times unable to report on their situation and feelings with the accuracy that is required for impact evaluations. Their memory or outlook on their situation before the intervention may change over time. The time period between baseline and follow-up must be carefully selected to allow sufficient time for a

change to take place (e.g. one week may be insufficient to detect a change in poverty after cataract surgery).

- **Control group of PWDs (represents the 'counterfactual' – i.e. what would have happened in the absence of the intervention):** Comparison of change in outcomes between PWDs who have received the intervention and **PWDs who have received no intervention** (or an alternative intervention such as the standard care). This comparison is needed to **show causality** between the intervention and the outcomes. For example, significant improvements in the average participation of children with disability (CWD) and the poverty of their households over 1 year *could* be due to the fact that they attended CBR. However, it could also be that improvements were a result of normal (age-related) child development, or that crop production was particularly good that year. The control group of PWDs demonstrates what would have happened in the absence of the programme or intervention of interest (called the counterfactual), so that the proportion of change attributable to the intervention can be estimated.
- **Control group of able-bodied peers (represent the 'norm'):** Comparison of change in outcomes between PWDs receiving the intervention and able-bodied peers facilitates the meaningful interpretation of results. Rather than being able to just say "Participation in children improved by 50% and household poverty was reduced by 30% as a result of attending CBR", one might be able to say "Participation in children improved to the same level as non-disabled peers of the same age and sex, and household poverty improved to the same level as the general community". Thus control groups of non-disabled able-bodied can give valuable information about how interventions may have reduced gaps or inequalities between PWDs and able-bodied people.

1.4.5. Types of Study Design

It is advisable to consult an experienced researcher such as an epidemiologist or statistician in the early stages of planning an impact evaluation in order to ensure that the study is designed and powered to answer the research questions in a robust way. A variety of study designs can be used to assess impact:

- **Case-series** are observational studies that follow PWDS over time. For instance, a case series of the impact of physiotherapy would follow a group of children with a musculoskeletal impairment who receive physiotherapy over time to assess changes in their outcome. They do not have any control group, and so cannot make robust conclusions about causality or interpretations of change (as explained in 1.4.4).
- **Randomised controlled trials (RCTs)** are currently the gold-standard design for testing the effectiveness of an intervention. PWDs would be randomly assigned to a treatment group (e.g. physiotherapy) and a control group (e.g. no physiotherapy or standard care). The randomisation means that the

characteristics of the two groups will be similar (e.g. age, sex, severity of impairment), and the only difference is that one group receives the intervention and the other does not. This means that any difference in changes over time between the groups can be attributed to the intervention and not any systematic differences (bias) between the two groups at baseline (e.g. differences in age or severity of impairment). However RCTs are not always feasible or ethical to undertake. For instance, it may not be ethically feasible to withhold treatment from one of the study arms. It is also difficult to use RCTs to evaluate the impact of non-discrete and non-medical rehabilitation services such as CBR where it may be impossible to prevent exposure of community members to the programme.

- **Quasi-experimental designs (QE)** are similar to case series, except that a control arm is included as well as the intervention arm. In this study design the researcher has no control over the allocation of PWDs to different treatment options, as they are self-selected. This is therefore an observational study design and compares the changes in outcomes in 'natural' groups (e.g. PWDs receiving physiotherapy compared to PWDs who do not take up physiotherapy services offered to them). The problem here is systematic differences between groups that may affect the outcomes of interest. For example, people who choose not to take up services that are offered to them may also be more likely to live far away from a service in a town and so be less likely to attend physiotherapy than those who live nearby. They may also have fewer opportunities to earn money than those living nearby the town. This means that differences between the control and intervention groups in terms of outcome may not be due to the treatment, but because of other systematic differences between the groups. It is possible to account for such differences in the analyses so that a reliable interpretation of impact can be made (e.g. regression analyses, propensity scoring) and this will usually require the assistance of a statistician. Resources for identifying appropriate methods is the World Bank Handbook on Impact Evaluations²³ and the website of the International Initiative for Impact Evaluations (3ie; <http://www.3ieimpact.org/>).

1.4.6. Sample Size

A sufficiently large sample size is required to detect change among people who have received an intervention, and to identify differences between intervention and control groups. The sample size needed depends on the following variables:

1. The required confidence level (usually 95%), i.e. the probability that if two samples differ this reflects a true difference in the two populations
2. The required power (usually 80%), i.e. the probability that if two populations differ the two samples will show a significant difference
3. The ratio of those "exposed" (e.g. received intervention) to those "not exposed" (e.g. control group)
4. The expected frequency of the outcome in the unexposed group
5. The strength of the association expected (measured as a relative risk).

The required sample size can be calculated using standard statistical tools, such as Epi info. It is recommended that a statistician is asked to help estimate the required

sample size. If the sample size is too small then the study may fail to identify an impact of the intervention, or a difference between the control and intervention group, and so all the efforts setting up the study will not be worthwhile.

1.4.7. Economic evaluation, QALYS and DALYS²⁴⁻²⁵

The results of an impact evaluation may show that one model of CBR has a greater impact (e.g. on improving QOL) than another model. However, the greater impact may come at a much higher cost and so the value for money or 'cost-effectiveness' is an important consideration for a programme, especially those with scarce resources. An economic evaluation may therefore be an important component of an impact evaluation. This requires the costs of a programme to the client and/or provider to be compared to the net increase in a primary outcome of interest (e.g. QOL). The outcome must be available as a single score, which may be produced by summing the responses of a self-report questionnaire (e.g. of QOL) into a total score, among other methods. The impact assessment tools that we review below are appropriate measures of effectiveness in economic evaluation. It is useful to seek the assistance of a health economist when measuring the cost of an intervention.

There are three main types of economic evaluation:

1. **Cost-benefit analysis (CBA).** The costs of the intervention are compared to the gains in terms of monetary benefit. There are different techniques for placing a monetary value on benefit, and these include estimating increased productivity, or the willingness to pay for the intervention by the client. If the monetary benefits exceed the costs then the intervention is believed to be cost-effective.
2. **Cost-effectiveness analysis (CEA).** The costs of the intervention are compared to the gains in terms of disease-specific outcomes, for instance, improvements in visual acuity. It is difficult to compare interventions targeting different conditions using a CEA if effectiveness is measured in terms of condition-specific measures. Generic CCOs scores (e.g. QOL, health status) can also be used for CEA.
3. **Cost-utility analysis (CUA).** The costs of the intervention are compared to gains in terms of **Quality Adjusted Life Years (QALYs)**. A QALY is a universal unit of outcome that combines net changes in both length and quality of life that has been gained from an intervention. Quality of life is assessed in terms of utility values (UV) which range from zero (death) to one (perfect health) with all other health states lying between these boundaries. QALYs are then calculated by multiplying the length of life by the quality of life. Living in perfect health for one year would score one QALY, equivalent to living at a UV of 0.5 for two years or a UV of 0.25 for four years. The impact of an intervention in terms of QALYs gained takes into account both the amount that life has been increased and the amount that quality of life has improved as a result of the intervention. Imagine a scenario where an intervention improved the UV from 0.25 to 0.75, but had no

impact on length of life which remained at 10 years. This means that the QALYs gained by the intervention are 0.5 (UV increase) multiplied by 10 (life expectancy), which is 5 QALYs.

There are a variety of methods for assigning a UV to a health state:

a) Direct elicitation of preferences. These include the standard gamble method and the time trade-off method. These methods are complex and time-consuming and not recommended for CBM studies. Instead, we recommend that published UVs connected with specific impairments/disabilities are used.

b) Tools with preference weights. UVs can also be assigned based on responses to standardised questionnaires (e.g. SF-36) which have specific weights attached to them. These preference weights are not available for all standardised questionnaires and are generally not available for LMICs, so that the preference weights from high income countries need to be used which may not be appropriate.

There are concerns about the use of UVs for assessment of disability.²⁶ UVs scores are assigned according to health states, and disability is not determined by health (or impairment) alone. There are also concerns that the QALY assigned to people with disabilities are lower than for people without disabilities, implying that their lives have less value. In an extreme case, saving the life of someone without disability would result in more QALYs gained than saving the life of someone with a disability. Nevertheless the tools used to measure utilities are reviewed here for completeness and CUA are important tools in economic evaluations of interventions. The main strength of CUA is that QALYs are universal concepts and therefore allow the comparison between different intervention or impairment types.

An alternative measure to the QALY is the **disability-adjusted life year (DALY)**.²⁶⁻²⁸ This is a measure of disease burden, expressed as the number of years lost due to ill-health, disability or death. It is calculated by taking the sum of the years of life lost and the years of lived with disability. One DALY is therefore equal to one year of healthy life lost. DALYs do not take into account the degree of disability, in comparison to QALYs which do. DALYs are also criticised for equating health with the number of years lived without disability. In addition, DALYs are less frequently used than QALYs in economic evaluation. For these reasons we will not consider DALYs further in this review.

1.5. Aim & Objectives

The aim of this study is to undertake a systematic review of tools that can be used to measure the impact of rehabilitation services in the lives of children and adults with disability in low and middle income countries in Asia, Africa and Latin America.

The objectives are as follows:

- To identify generic tools available for measuring client-centred outcomes (A&P, QOL) and their families (household poverty) internationally
- To critically review generic tools available for measuring CCOs against criteria that are relevant to conducting impact evaluations in LMICS
- To suggest the best tools to use for assessment of the impact of CBM programmes

1.6. Scope of the review

In this review, we will identify and critically evaluate tools for evaluating the impact of rehabilitative services for PWDS in low- and middle-income countries. Tools will be reviewed if they fulfil the following criteria:

- Measure **CCOs** relevant to evaluating the impact of rehabilitation in the lives of PWDS in LMICs. For instance Poverty, A&P, QOL and HRQOL.
- Are **generic** tools that are applicable across all impairment categories and programmes, rather than tools that are specific to a particular impairment or that are disease-specific. For instance, we will include tools that measure generic health-related quality of life, rather than vision-related quality of life.
- Can be used to evaluate CCOs for **adults or children** with disabilities.

2. METHODS

2.1. Search strategy

Three search strategies (below) were used to identify generic and validated instruments measuring CCOs for adults and children with disabilities. These were designed to:

- a) identify those tools that are already available and in use in rehabilitation research in LMICs, as well as
- b) to identify the best tools that have been developed internationally that could be used in rehabilitation research (if they are not already).

- **Strategy 1 (S1)** - We conducted a systematic search to identify studies evaluating the impact of rehabilitation in the lives of children and adults with disability in Latin America, Africa and Asia, and the CCO tools that were used.
- **Strategy 2 (S2)** - We identified and analysed 20 reviews of generic instruments for adults and children. There were 10 reviews of adult measures,²⁹⁻³⁸ including 4 that were published recently in 2008-2009 and were specifically about participation and disability.³¹⁻³⁴ There were 10 reviews of childhood measures,³⁹⁻⁴⁸ of which the most recent (Solans *et al.*, 2008⁴⁸) was a systematic review of generic and disease-specific quality-of-life tools for children and adolescents.
- **Strategy 3 (S3)** - We conducted a systematic search of generic CCO tools developed and validated for adults and children since the beginning of 2000.

2.2. Electronic searching

Medline, Embase, Global Health, and the Web of Science were systematically searched for scientific papers in S1 and S3. The search for new generic tools published since 2000 (S3) additionally used PsychINFO. Impact studies in LMICS (S1) were also searched for in the grey literature using the Source database (<http://www.asksource.info/>). Final searches were run between April (S1) and June (S3) 2010 and limited to English language papers.

The S1 search combined text and thesaurus terms (where available) for 'impact', 'rehabilitation', 'disability', 'PWDs', and 'Asia/Africa/Latin America' to identify impact studies in Asia, Africa and Latin America. A range of synonyms for each of these terms were used, for example terms for 'impact' included 'effectiveness/evaluations/outcomes/ follow-up', and synonyms for rehabilitation included 'services/interventions'. Uzbekistan and Tajikistan were also included because CBM supports some projects in these countries of Eastern Europe. The search was not limited by date of publication. The full search is included in Appendix A.

Searches (S1) yielded a total of 801 articles across databases, which were reduced to 501 after the removal of duplicates.

The S3 search combined text terms for different subjective, multidimensional concepts of outcome relevant to PWDs, with various text terms for 'tool', 'generic' and 'valid' to identify papers reporting the development and/or validation of generic tools between 2000-2010. The multi-dimensional concepts of outcome that were included in the search were: activities, participation, disability, quality-of-life, activities of daily living (ADL), wellbeing, health status, functional status, social functioning, psychosocial functioning. These were informed by the results of Stage 1. Synonyms were used for all terms. See Appendix B for the S3 search terms. Searches (S3) yielded a total of 5491 articles across databases, which were reduced to 2428 after the removal of duplicates.

2.3. Expert consultation

In April 2010 a mailing list of >150 members of the International Disability and Development Consortium (IDDC) and CBM Advisory Working Group members were sent an email inviting contributions for any studies or articles about evaluating the impact of rehabilitation in the lives of PWDs and their families. They were also asked to share relevant contacts and tools used or under development for this purpose.

2.4. Study selection - Inclusion and Exclusion criteria (S1)

Studies identified through S1 were included if the main focus of the paper was the impact or effectiveness of a service(s) or intervention(s) for people with disabilities, in a LMIC in Asia, Africa, Latin America Uzbekistan or Tajikistan. World Bank country classifications were used.⁴⁹ Studies in high-income countries (Hong Kong, Israel) were also included, due to the potential applicability of Hong Kong language versions elsewhere in Asia, and for the interest of CBM projects in Israel. Studies were included if they measured a self-reported CCO (e.g. ADL, activities, participation, quality-of-life, health status, functional status, wellbeing) using a scale at two time points. Those that assessed clinical outcomes only or measured subjective outcomes by clinician observation or judgement were excluded. Studies basing the measurement of impact on retrospective reporting of CCOs were also excluded.

2.5. Tool selection - Inclusion and Exclusion criteria (S1, S2, S3)

Instruments identified in S1, S2 and S3 were included in the review of tools if they were generic, quantitative measures of disability, activities and/or participation (A&P), quality of life (QOL), health-related quality of life (HRQOL), activities of daily living (ADL), wellbeing, health status or functional status, targeting adult or child populations. Instruments were eligible if they had standardised content and were self-reported by adults or children with disabilities, or a close family member or caregiver (proxy).

Tools that were excluded were: disease or condition-specific; individualised tools with non-standardised content (including qualitative tools); tools measuring or testing objective outcomes in a clinical environment and/or reported by health professionals only; indicators developed for routine monitoring and evaluation rather than the quantitative measurement of outcomes; tools developed for adults and then used with children without any specific adaptation to children; classification, screening, developmental and prognostic tools; tools measuring satisfaction with services; tools measuring single dimension concepts (e.g. walking, mobility, pain, fatigue), or mediating outcomes (e.g. coping, personality, playfulness).

2.6. Selection and Extraction Procedure

The title and abstract of all articles identified in S1 and S3 were screened to identify papers that potentially met the inclusion/exclusion criteria (below). The full text of articles of potential eligibility were retrieved and read to make the final decision. Twenty percent of S1 articles were screened by two researchers (YA, SP) and the remainder of S1 and all of S2/3 were screened by one researcher (YA). A third person (HK) was consulted to determine eligibility when there were discrepancies regarding eligibility. The reference lists of all impact studies and reviews of CCO tools were searched to identify further impact studies and tools.

A standardised form was used to extract information about impact studies identified in S1 and all eligible tools identified in the process. The following characteristics about impact studies were extracted: authors/year; country; study design; population (adult, child); impairment categories of sample population; intervention type/name; CCOs evaluated; tools used to evaluate CCOs.

A list of tools was compiled from the impact evaluations (S1), the reviews (S2) and the search for new tools (S3). The original development papers (articles reporting the original development and tests of validity and reliability of each measure) for each tool were identified through electronic searching and the full text articles

retrieved. Papers reviewing the development and psychometrics of tools developed were also obtained (e.g. SF-36, WHOQOL⁵⁰⁻⁵¹). Additional searches were run in Medline and PROQOLID (The Patient-Reported Outcomes and Quality of Life Instruments Database) to identify country/language adaptations of eligible tools which have been developed for LMICS in Africa, Asia and Latin America. The searches in Medline combined text terms for each LMIC,⁴⁹ with the name and/or acronym of each tool on an 'AND' operator.

An additional search in WOK was conducted to find out how many times the original development paper had been cited since publication. While this cannot be used as an accurate measure of the intensity of use, we used it to identify tools at the extreme ends of the spectrum (i.e. those that have essentially not been used since development, and those that have been the most widely used). If there was more than one original development paper, the one cited the most times was used to calculate the Citation Score (number of citations/years since published). Citation Scores were not calculated for tools first published from 2007 onwards on the theory that it would take at least 3 years for the research community to publish studies using the new tool.

The following information was extracted for each tool: Full name, acronym, country (and language) of origin; target population; purpose of tool; concept measured; number of items; time to complete; respondent; names of dimensions or subscales; scoring (total/subscales); methods of item generation; evidence for validity, reliability and responsiveness. The strength of the methods of item generation with regard to developing a tool with content that is valid to the target population was rated (content validity), along with the strength of evidence for validity and reliability according to the criteria outlined below.

2.7. Ratings of content development and psychometric properties

Content development

Content validity is the extent to which a tool measures the concept of interest (e.g. Participation) for the target population of interest (e.g. AWDs). Evidence of content validity is supported by the methods used to develop the content, as well as statistical analyses (see below 'Psychometric properties').

Methods used to generate items in tools are:

- 1) Consultation with experts (e.g. clinical/academic)
- 2) Consultation with target population
- 3) Literature reviews
- 4) Reviews of the content of existing CCO tools

- 5) The use of a theoretical model (e.g. ICF)
- 6) Adaptation of an existing tool
- 7) Pilot/pre-tests with the target population to ensure that they are appropriate, comprehensible (wording) and comprehensive (in content)
- 8) Pilot/pre-tests with experts

Each measure was rated according to the number and/or type of methods used to generate the content. Where a tool was adapted from an existing measure, the methods used in the development of the latter were taken into consideration. Based on current standards for tool development, preference was given to studies which consulted the target population in the development of content, either during initial item generation (e.g. interviews) or during pilot testing/cognitive interviewing stage.

Tools were rated on content development as:

- (0) if none of the above were reported;
- (+) if 1 of the above methods were reported;
- (++) if 2-3 of the methods were reported;
- (+++) if 4+ methods were reported *excluding* consultation with the target group about the content (comprehensiveness) of the tool;
- (++++) if 4+ methods were used *including* consultation with the target group about the content of the tool (comprehensiveness).

Pilot/pre-testing was not considered consultation with the target group if input about the comprehensiveness of the content of the tool was not collected from the target population.

Psychometric Properties

For each instrument included in the review, the psychometric properties of reliability, validity, and responsiveness (sensitivity to change) were evaluated from original development papers following the same methods used in a recent review of childhood measures of QOL. These methods were based on recommendations in the scientific literature on the desirable characteristics of HRQOL instruments and updated with ongoing developments in guidelines and tools for the review of patient-reported outcome measures (COSMIN⁵²⁻⁵³, EMPRO⁵⁴).

The following psychometric properties were assessed:

a) Reliability

Reliability refers to the extent to which the instrument is free from random error, and was assessed through evidence of each scale's:

- internal consistency - a test of all items in a scale or subscale being homogenous and measuring the same construct
- test-retest reliability - a test of reproducibility/stability of repeated measurements for people who have not changed with regards to the underlying concept

Acceptable statistics for the measurement of internal consistency for total and subscale scores was Cronbach's alpha and/or KR-20 scores of >0.7 . Acceptable statistics for measurement of test retest reliability for total and subscale scores were intra-class coefficients (ICC) ≥ 0.7 . The evidence for reliability was summarised as⁴⁸:

(0) not reported;

(-) reliability is not acceptable in terms of either internal consistency and/or test-retest (<0.70 in 30% or more of the dimensions);

(+) only one type of reliability (internal consistency or test-retest) has been tested, with acceptable results;

(++) both internal consistency and test-retest stability are acceptable (>0.70 in 70% or more dimensions).

b) Validity

Validity is the extent to which an instrument measures what it intends to measure. This was assessed from evidence of:

- Structural validity - tests of whether the tool's structure (scales/subscales) reflects a priori expectations of a theoretical model
- Construct validity - tests of the extent to which a tool confirms a priori hypotheses about relationships to external variables
- Criterion validity - tests of the extent to which the tool correlates with the a gold-standard' tool measuring the same concept

Methods included to test structural validity included factor analyses; those for construct validity were the detection of differences between groups who are expected to differ (known groups differences) and associations with measures which are expected to correlate to varying degrees.

Evidence of validity was rated as⁴⁸:

- (0) not reported;
- (-) validity is not acceptable in one or more aspects (structural, construct and/or criterion);
- (+) one type of validity tested, with acceptable results;
- (++) two types of validity tested with acceptable results;
- (+++ all three types of validity tested with acceptable results.

c) Responsiveness (sensitivity to change)

Sensitivity to change refers to the ability of the questionnaire to detect important changes in the underlying concept over time (e.g. pre- and post-intervention), and is usually measured using the effect size (ES). In keeping with the review by Solans *et al.* 2008⁴⁸ a minimum ES of 0.2 was considered acceptable.

Responsiveness was rated as:

- (0) not reported;
- (-) assessed, but unacceptable (ES <0.2);
- (+) assessed and acceptable (ES ≥0.2).

2.8. Criteria for Short-listing and Recommendations

Of all tools that were included and reviewed, a few were shortlisted for recommendation for use by CBM in impact assessment according to the following criteria:

- **Conceptual origins**– Tools were preferred if they were developed from concept in one or more LMIC, because tools developed and validated in a LMIC in Asia, Africa and Latin America are likely to be more valid and appropriate for populations in these socio-economic/cultural settings
- **Respondent/Interviewer Burden** – Tools of shorter length (number of items) were preferred in order to minimise the time burden on respondents and assessors
- **Content development** – tools which rated highly on content development (see above), including the use of a model (e.g. ICF), were preferred.
- **Subscale and Total scores** – tools were preferred if they produced both a total and sub-scale scores so that they could provide both descriptive data on impact, and units of outcome for application in economic evaluation.
- **Reliability** – tools with strong evidence of reliability were preferred.
- **Validity** – tools with strong evidence of validity were preferred.
- **Responsiveness** – tools with evidence of the ability to detect important changes in the underlying concept were preferred. As responsiveness is not universally assessed in original development papers, evidence of responsiveness was not required for short listing, but evidence of responsiveness was reviewed for tools which were shortlisted. Where there was no evidence in original development papers, up to a maximum of 3 additional papers (the first 3) reporting responsiveness/effect size were identified and reviewed.
- **Cross-culturally adapted versions available** - tools for which many translations/adaptations across LMICS in Asia/Africa/Latin America are available were preferred.
- **Tools that are widely cited** in research were preferred so that results of new studies could be compared to existing literature. An indicator of the popularity of a measure was the Citation Score, calculated as the average number of times the original development paper had been cited since publication (see above).

In recommending shortlisted tools, the accessibility (e.g. copyright/licensing) was also taken into account.

3. RESULTS – REVIEW OF IMPACT EVALUATIONS

Strategy 1 searches identified a total of 51 studies evaluating the impact of rehabilitation for PWDs in Africa, Asia and Latin America. These eligible studies were identified from the following sources:

- 33 through electronic searching of published work (out of 501 published articles)
- 14 eligible studies from reference lists
- 2 from research published by LSHTM after the electronic searches were run⁵⁵⁻⁵⁶
- 2 ongoing (unpublished) studies identified through the IDDC network.

The methodological characteristics of these 51 studies are detailed in Table 3.1 and we summarise the key findings below:

- **Populations:** CWDs were substantially under-represented in impact evaluations compared to AWDs. While 49 studies investigated rehabilitation for AWDs, only 8 studies included children in the sample population, and of these all were wholly or mainly focused on CCOs in the AWDs or the caregivers of CWDs.
- **Impairment categories:** Populations with all impairment types were represented in the impact assessments, although almost half (21/51) were focused on people with mental illness, especially schizophrenia. Most studies investigate a service or intervention for people with a specific impairment or diagnosis; 6 were comprehensive to people with different categories of impairment. All of the latter evaluations were also comprehensive to across age groups (children/adults) as well as impairment categories.
- **Geographical distribution:** About a third of studies (n = 16) were located in high-income countries (Israel and Hong Kong) and were included out of interest for CBM's programmes in Israel, as well as for tools applicable in Chinese-speaking countries. The vast majority of the 35 studies in LMICs were based in Asia (n = 26, especially India), with very few conducted in Africa (n = 6) or Latin America (n=2). Three studies evaluated services across 2-3 continents (Lagerkvist, 1992⁵⁷; Polack *et al.* 2010⁵⁶; HI Belgium).
- **Evaluation Design:** The type of study design was quasi-experimental (n=19), RCT (n=16) or case-series (n=14). All but 2 of the RCTs evaluated interventions and services for people with mental illness. Half of the case-series studies evaluated CBR programmes. Only 2 studies evaluating CBR programmes or services used a comparison group.
- **Measurement of CCOs:** Many different concepts of client centred outcomes were measured. Most used impairment/condition-specific tools, tools adapted for their own studies (made up mostly of single-item survey-type questions); or tools involving clinician observations and/or ratings.
- **Generic CCO tools:** A total of 7 tools used in studies met the eligibility criteria for generic tools to be carried forward for further review; these were published between 2000 and 2010. These were the Activity Card Sort (ACS), Community-Generated Index of Functional Impairment (CGI-FI), Euroqol EQ-5D (EQ5D), the Personal Wellbeing Index (PWI), the Participation Scale (P-Scale); the WHO Disability Assessment Schedule v2.0 (WHODAS 2), the WHO Quality of Life instrument (WHOQOL-BREF).

Table 3.1. Studies investigating the Impact of Rehabilitation Interventions and Services in the Lives of People with Disabilities in Low and Middle Income countries in Africa, Asia, Latin America, Israel and Hong Kong.

| Study | Design | Country | Age grp | Impairment group(s) | Intervention(s) | Target | CCOs measured (tool used; bold font indicates generic measure included reviewed) |
|---|--------|-----------|---------|--|--|--------------|--|
| 1 Chatterjee <i>et al.</i> 2009 ⁵⁸ | CS | India | A | Mental (Sz; Bip; Psy) | CBR | PWD | 1) Disability (WHODAS 2.0) 2) Social Outcomes (List of social activities and assets acquired) |
| 2 Srinivasa <i>et al.</i> 2005 ⁵⁹ | CS | India | A | Mental (Sz) | Psychosocial support; medication (outreach) | PWD + Family | 1) Disability (IDEAS [Ⓢ]) 2) Family burden (FBS [Ⓢ]) 3) Economic burden [Ⓢ] |
| 3 Patel <i>et al.</i> 2003 ⁶⁰ | RCT | India | A | Mental (Anx; Dep) | Antidepressant vs. Placebo vs. psychological treatment | PWD | Disability (BDQ [Ⓢ]) |
| 4 Ran <i>et al.</i> 2003 ⁶¹ | RCT | China | A | Mental (Sz) | Psycho-educational family intervention + medication vs. Medication alone vs. Control | PWD | 1) Disability & Functioning (GPIS [Ⓢ] + SDSS [Ⓢ]) 2) Attitudes & Beliefs towards PWD |
| 5 Bolton <i>et al.</i> 2003 ⁶² | RCT | Uganda | A | Mental (Dep) | Group Interpersonal Psychotherapy | PWD | Dysfunction (CGI-FI) |
| 6 Xiong <i>et al.</i> 1994 ⁶³ | RCT | China | A | Mental (Sz) | Family group counselling vs. Standard care | PWD + Family | 1)Overall Functioning (GAF [†]) 2)Psychosocial dysfunction (SDSS [Ⓢ]) 3)Family burden [Ⓢ] |
| 7 Chien <i>et al.</i> 2004 ⁶⁴ | RCT | Hong Kong | A | Mental (Sz) | Mutual Support Group vs. Standard care | Family | 1)Family burden (FBS [Ⓢ]); 2)Family functioning (MFAD) |
| 8 Zhang <i>et al.</i> 1994 ⁶⁵ | RCT | China | A | Mental (Sz) | Family intervention (counselling & education) vs. Standard care | PWD | Overall level of functioning (Global assessment Scale [Ⓢ]) |
| 9 Chien <i>et al.</i> 2005 ⁶⁶ | RCT | Hong Kong | A | Mental (Sz) | Mutual Support group vs. Psycho-education vs. Standard care | PWD + Family | 1) Family Functioning (MFAD), 2) PWD Functioning (SLOFS [†]) |
| 10 Chien <i>et al.</i> 2004 ⁶⁷ | RCT | Hong Kong | A | Mental (Sz) | Mutual support vs. Psycho-education vs. Standard Care | PWD | Psychosocial Functioning (SLOFS [†]) |
| 11 Hasson-Ohayon <i>et al.</i> 2007 ⁶⁸ | RCT | Israel | A | Mental [Ⓢ] (Sz; Dep; Bip; Anx; Eat; Per; Psy) | Illness Management and Recovery program (educational) vs. Standard care | PWD | 1) Progress towards personal goals (IMRS [†]) 2) Coping 3) Perceived Social support |
| 12 Tsang <i>et al.</i> 2010 ⁶⁹ | RCT | Hong Kong | A | Mental(Sz; Bip; Dep; Per) | Integrated Supported Employment (ISE) programme vs Individual Placement Support | PWD | 1) Wellbeing (PWI) 2) Employment rate/tenure (indicators) 3) Coping/self-efficacy |
| 13 Xiang <i>et al.</i> 1994 ⁷⁰ | RCT | China | A | Mental [Ⓢ] (Sz; affective psychoses) | Psycho-educational Family Intervention + Drug treatment vs. Drug treatment only | PWD | 1) Social disturbance (SDSS [Ⓢ]) |
| 14 Dias <i>et al.</i> 2008 ⁷¹ | RCT | India | A | Mental (dementia) | Home Care Advisors vs. No intervention (waiting list) | Carer | 1) Caregiver mental health (GHQ [Ⓢ]), 2) Caregiver Burden (Zarit), 3) ADL (EASI [Ⓢ]) |
| 15 Chatterjee <i>et al.</i> 2003 ⁷² | QE | India | A | Mental [Ⓢ] (Sz) | CBR vs. outpatient clinic care | PWD | Disability (WHODAS 2.0) |
| 16 Wong <i>et al.</i> 2009 ⁷³ | QE | Hong Kong | A | Mental (Sz; Bip; Dep; OCD) | New vs. standard case- management model in halfway houses | PWD | 1) Life skills(LSS); 2) QOL (QLS [Ⓢ]) |
| 17 Chan <i>et al.</i> 2000 ⁷⁴ | QE | Hong Kong | A | Mental [Ⓢ] (Sz) | Community Case Management Service vs. Conventional Community Psychiatric Nursing Service | PWD | 1) Functional level (SLOFS [†]) |

| | | | | | | | | |
|----|--|-----|----------------------|-------|---|--|--------|---|
| 18 | Tsai et al. 2005 ⁷⁵ | QE | Taiwan | A | Mental ^ψ (Sz; Bip; Par; OMD) | Hospital-based home-care model vs. conventional outpatient follow | PWD | Social function (SFS ^ϕ) |
| 19 | Dor & Savaya. 2007 ⁷⁶ | QE | Israel | A | Mental (not stated) | Integrative vs. Segregative Psychosocial Recreational Program | PWD | 1) Leisure activities + Quality of social life (WQLI ^ϕ) 2) Loneliness 4) Perceived Social support |
| 20 | Chisholm et al. 2000 ⁷⁷ | QE | India, Pakistan | A | Mental (affective & neurotic disorders) | Mental Health Care Programme (Integrated Care) vs. Standard Primary Health Care System | PWD | 1) Disability (BDQ ^ϕ) 2) QOL (WHOQOL-BREF) 3) Education, Employment, Income ^ψ |
| 21 | Thirthalli et al. 2009 ⁷⁸ | QE | India | A | Mental ^ψ (Sz) | Continuing medication vs. Starting medication vs. No medication | PWD | Disability (IDEAS ^ϕ) |
| 22 | O'Toole et al. 1988 ⁷⁹ | CS | Guyana | C | Mix (Hear; Epi; Speak, Phys, CP; DS) | CBR | Parent | 1) Emotional disturbance in mothers 2) Parent attitudes/feelings incl. towards child (CRS) |
| 23 | Lagerkvist 1992 ⁵⁷ | CS | Philippines Zimbabwe | A + C | Mix (Mov; Learn, Vis, Hearing + Speak; Seiz; SB). | CBR | PWD | Ability (incl. Physical independence (ADL) and social integration ^ψ) |
| 24 | Nordholm & Lundgren-Lindquist 1999 ⁸⁰ | CS | Botswana | A + C | Mix (Mov; Vis; Learn; Hear + Speak; SB; Sei; Multi) | CBR | PWD | 1) ADL ^ψ 2) QOL (satisfaction with various aspects of life) ^ψ |
| 25 | Finstamm et al. 1988 ⁸¹ | CS | Pakistan | A + C | Mix (Mov; Vis; Learn; Hear + Speak; Mental; Seiz) | CBR | PWD | 1) Function (WHO's CBR Manual) |
| 26 | Lundgren-Lindquist & Nordholm 1996 ⁸² | CS | Botswana | A + C | Mix (incl. mobility) | CBR | PWD | 1) ADL ^ψ 2) QOL (satisfaction with various aspects of life) ^ψ 3) Working/Schooling ^ψ |
| 27 | Ravi et al. 2004 ⁸³ | RCT | India | A | Leprosy (neuritis) | Ambulatory care (education on management) vs. inpatient care | PWD | QOL ^ψ |
| 28 | Katz et al. 1978 ⁸⁴ | QE | Israel | A | Multiple (Neurological, Cog, Emotional, Social) | Sheltered Rehabilitation workshop vs. Controls | PWD | Satisfaction ^ψ |
| 29 | Daniel & Manigandan. 2005 ⁸⁵ | QE | India | A | Physical (Paraplegia from SCI) | 'Stop and smile' group therapy vs Control group | PWD | 1) QOL (WHOQOL-BREF) 2) Leisure satisfaction (LeiSS) |
| 30 | Dai et al. 2002 ⁸⁶ | QE | Taiwan | A | Physical (hip fracture) | In-hospital multidisciplinary rehabilitation program vs. standard care | PWD | Basic ADL (BADL) |
| 31 | Ray & Nair. 1990 ⁸⁷ | QE | Singapore | A | Physical | Senior Citizens' Health Care Centre (Day care vs Rehabilitation) | PWD | ADL Status ^{ψ†} |
| 32 | Chiu et al. 2001 ⁸⁸ | QE | Taiwan | A | Physical (stroke) | Hospital chronic care vs. Nursing home placement vs. Home nursing care vs. Family care | PWD | Physical functional status (Katz ADL Scale) [†] |
| 33 | Nir & Galinsky. 2000 ⁸⁹ | CS | Israel | A | Physical | Geriatric Rehabilitation Unit | PWD | 1) Independence in ADL [†] , 2) Social roles' Family social network ^ψ |
| 34 | Gershon & Srinivasan 1992 ⁹⁰ | CS | India | A | Unspecific (Leprosy) | CBR | PWD | Respect/recognition in the family; Occupational status; Economic benefit; Housing type ^ψ |
| 35 | Eide 2006 ⁹¹ | CS | Palestine | NR | Unspecific | CBR | PWD | ADL, family life & social participation outside the family ^ψ |

| | | | | | | | | |
|----|--|-----|--------------------------------------|----------|--|--|------------------|---|
| 36 | Oupra <i>et al.</i> 2009 ⁹² | QE | Thailand | A | Unspecific (stroke) | Nurse-led Supportive Educative Learning programme vs. Usual care | Family Caregiver | 1) Caregiver QOL (GHQ-28) ^ψ 2) Caregiver strain Index |
| 37 | Keren <i>et al.</i> 2004 ⁹³ | CS | Israel | A | Unspecific (stroke) | Rehabilitation therapy | PWD | 1) Activity level (FIM) [†] 2) Functional Assessment (RICFAS) |
| 38 | Hartman-Maeir <i>et al.</i> 2007 ⁹⁴ | QE | Israel | A | Unspecific (stroke) | CBR v No intervention | PWD | 3) Leisure participation (ACS), 2) Functional status (FIM) [†] , 2) ADLs (IADLq) [†] , 4) Life satisfaction (LiSat-9) ^ψ , 5) Health status (SIS) ^ψ |
| 39 | Saxena <i>et al.</i> 2006 ⁹⁵ | CS | Singapore | A | Unspecific (stroke) | Inpatient rehabilitative care | PWD | ADL (BI) [†] |
| 40 | Siu & Chui 2004 ⁹⁶ | QE | Hong Kong | A | Physical (RA) | Community rehabilitation service 3 phases vs. 1 phase (self-enrolment) | PWD | 1) Health status ^ψ 2) Self-management behaviour, 3) Self-efficacy |
| 41 | Gupta <i>et al.</i> 2009 ⁹⁷ | CS | India | A | Physical (SCL) | Inpatient neurological rehabilitation | PWD | Functional ability (BI) [†] |
| 42 | Gupta <i>et al.</i> 2008 ⁹⁸ | CS | India | A | Physical (SCL) | Inpatient neurological rehabilitation | PWD | Functional ability (BI) [†] |
| 43 | Weiss <i>et al.</i> 2004 ⁹⁹ | QE | Israel | A | Movement (stroke) | Institutional rehab v Home rehabilitation | PWD | Mobility and ADL (BI [†] ; FAI ^ψ) |
| 44 | Hershkovitz & Brill. 2007 ¹⁰⁰ | CS | Israel | A | Cognitive (orthopaedic + stroke) | Rehabilitation day hospital | PWD | ADL (NEAI) ^ψ |
| 45 | Shechtman & Gilat. 2005 ¹⁰¹ | QE | Israel | C | Learning | Educational-didactic group vs. counselling | Parent | 1) Parent Attitudes towards child, 2) Parental Stress, 3) Parental Sense of control |
| 46 | Olley <i>et al.</i> 2001 ¹⁰² | RCT | Nigeria | A | Seizures (Epi) | Psycho-educational programme vs. Control (waiting list) | PWD | Psychopathology |
| 47 | Laviers <i>et al.</i> 2010 ¹⁰³ | CS | Zanzibar | A | Visual (presbyopia) | Correcting presbyopia with spectacles | PWD | 1) Visual function & QOL/Life Satisfaction ^ψ 2) Satisfaction with spectacles ^ψ |
| 48 | Polack <i>et al.</i> 2010 ¹⁰⁴ | QE | Philippines Bangladesh & Kenya | A | Visual (cataract) | Surgery vs. non-visually impaired controls | PWD | HRQOL (EuroQOL , WHO/PBD VF20 ^ψ) |
| 49 | Polack <i>et al.</i> 2010 ⁵⁶ | QE | Philippines Bangladesh & Kenya | A | Visual (cataract) | Surgery vs. non-visually impaired controls | PWD | Time-use (World Bank Living Standards Measurement Survey Stylised activity list ^ψ) |
| 50 | HI Belgium - unpublished | QE | Asia, Africa, L. America | A + C | Mix: All beneficiaries of service | CBR vs. able-bodied controls (neighbours) | | 1) Poverty or education ^ψ , 2) Equal access basic services (e.g. livelihood) ^ψ , 3) Social integration ^ψ |
| 51 | AIFO Italy, WHO DAR - unpublished | QE | India | A + C | Mix: (Phys, Mental; Learn; Vis; leprosy, hear + speak etc) | CBR vs. No intervention (neighbouring district) | | 1) Participation (P-Scale), 2) ADL (WHO CBR manual) 3) Access to services (health, education etc) |

ψ Tools and questions (often single-item survey questionnaires) developed/adapted for study; **†** Clinician observation/judgement tools; **ψ** impairment or disease-specific tools. **SFS, SLOF, LLS & RICFAS** - original development papers/manuals inaccessible

ACS = Activity Card Sort; **ADL** = Activities of Daily Living; **AIFO** = Italian Association Amici di Raoul Follereau; **Anx** = Anxiety disorder; **BADL** = Basic ADL (inaccessible; in Chinese); **BDQ** = Brief Disability Questionnaire; **BI** = Barthel Index; **Bip** = Bipolar disorder; **CGI-FI** = Community-generated Index of Functional Impairment; **CP** = Cerebral Palsy; **CRS** = Child Rating Scale; **CS** = Case-series; **CWD** = Child with Disability; **Dep** = Depression; **DS** = Down's syndrome; **Eat** = Eating disorder; **Epi** = Epilepsy; **EuroOL** = EuroQOL EQ5D & VAS; **FAI** = Frenchay Activities Index; **FIM** = Functional Independence Measure; **GAF** = Global Assessment of Functioning Scale; **GHQ** = General health Questionnaire; **GPIS** = General Psychiatric Interview Schedule and Summary Form; **Hear** = Hearing impairment; **HI** =

Handicap International; **IDEAS** = Indian Disability Evaluation Assessment Scale; **IMRS** = Illness Management and Recovery Scale; **IADLq** = Instrumental ADL questionnaire; **LSS** = Life Skills Scale (inaccessible as published in Hong Kong only); **LeISS** = Leisure Satisfaction Scale; **Li-Sat-9** = Life Satisfaction questionnaire; **MFAD** = McMaster Family Assessment Device; **Mov** = Moving impairment; **Multi** = Multiple categories of impairment; **NEAI** = Nottingham Extended ADL Index; **NR** = not reported (states 'individuals with disabilities' only); **OCD** = obsessive compulsive disorder; **OMD** = Organic mental disorder; **PAR** = Paranoia; **PER** = Personality disorder; **Phys** = Physical impairment; **PND** = Post-natal depression; **Psy** = Psychoses; **PWI** = Personal wellbeing Index; **PWD** = Person with Disability; **P-Scale** = Participation Scale; **QE** = Quasi-experimental; **QLS** = Quality of Life Scale; **QOL** = Quality of Life; **RA** = Rheumatoid arthritis; **RCT** = Randomised Controlled Trial; **RICFAS** = Rehabilitation Institute of Chicago Functional Assessment Scale; **SB** = Strange behaviour (e.g. mental illness); **SDSS** = Social disability screening schedule; **Seiz** = Seizures & fits; **SIS** = Stroke Impact Scale; **Speak** = Speech impairment; **SCI** = Spinal Cord Injury; **SCL** = spinal cord lesions; **SFS** = Social Function Scale; **SLOFS** = Specific Level of Functioning Scale; **Sz** = schizophrenia; **Vis** = Visual impairment; **WHO** = World Health Organisation; **WHO DAR** = WHO Disability & Rehabilitation; **WHODAS 2.0** = WHO Disability Assessment Schedule version 2.0; **WHOQOL-BREF** = WHO Quality of Life Instrument- BREF; **WHO/PBD VF20** = WHO Prevention of Blindness and Deafness 20-item Visual Functioning Questionnaire; **WQLI** = Wisconsin QOL Index.

4. RESULTS - REVIEW OF TOOLS

From S1, S2 and S3 searches, a total of 87 tools were identified that met the eligibility criteria outlined in section 2.5. In addition to the 7 tools identified from impact evaluations (S1), reviews of CCO tools (S2) identified another 65 tools developed and used internationally. A further 10 tools developed and published since 2000 were identified (S3). Finally, 5 tools were identified when investigating and extracting information about tools through cited reference searches and websites of tool providers.

There were a total of 37 tools measuring outcomes in Adults, and 50 in children. Only one tool overlapped between adults and children (the Health Utilities Index).

Tools measuring different concepts (Activities, Participation, QOL/Health Status) for adults and children are presented separately below.

Table 4.1. Summary of the identification of tools.

| | S1 | S2 | S3 | Additional | Total |
|----------|----------|-----------|-----------|------------|-----------|
| Adults | 7 | 22 | 5 | 3 | 37 |
| Children | 0 | 43 | 5 | 2 | 50 |
| Total | 7 | 65 | 10 | 5 | 87 |

4.1. Tools measuring Activities in Adults

The ICF defines an activity as 'executing a task or action' and participation as 'involvement in a life situation'. As ICF categories are combined under 'Activities & Participation' it is sometimes unclear as to which categories constitute one or the other. However, it is understood that items such as 'self-care' and 'fine hand use' constitute 'activities' rather than 'participation'.

A total of 11 tools that include activities in adults were included in the review (Table 4.2). Many of the tools measure activities including ADLs (e.g. self-care, physical-maintenance) as part of wider concept, namely Participation. There is therefore much overlap in those tools presented here and for Participation measures.

The recommended tools for measurement of activities in impact assessment are:

1) The World Health Organisation Disability Assessment Schedule 2.0

(**WHODAS 2.0**) has been under development and in use for several years under the acronym of WHODAS II, although Üstün *et al.* 2010¹⁰⁵⁻¹⁰⁶ have recently published the User Manual and a paper summarising the development of the scale. Note that the WHODAS 2.0 is an entirely different tool to the WHO/DAS¹⁰⁷ which is a psychiatric disability assessment that was later revised as the Groningen Social Disabilities Schedule (GSDS).¹⁰⁸

WHODAS 2.0 was developed to measure the impact of a health condition in a wide range of applications at the population level (surveys, registers, clinical trials) or in clinical practice (patient monitoring). Although the specific concept measured is unclear from the manual (e.g. it states it measures 'health and disability', 'functioning and disability', 'functioning', in different places), it has been developed specifically to reflect the ICF. The content of the WHODAS 2.0 includes activities such as washing, eating, dressing, standing for long periods/distances, moving inside the home, getting out of the home; standing up from sitting down.

The WHODAS 2.0 asks respondents how much difficulty they have had in the past 30 days with: understanding and communicating, getting around, self-care, getting along with people, life activities, and participation in society. It produces a subscale for each of these 6 dimensions, as well as a total score.

The WHODAS 2.0 was the only tool that met all the preferred criteria:

- Content developed from the ICF model, consultations with the target population, expert review and a review of 300 outcomes tools.
- Content was developed simultaneously across 19 countries including LMICS in Africa (Nigeria), Asia (Cambodia, China, India, Lebanon) and Latin America (Cuba, Peru)
- Tool can be used with adults of all ages (≥ 16 yrs)
- Feasible to use both long (36 item - 20 mins) or the short version (12 item - 5 mins). A two-part 12+24 item version is also available to save time by using the first part to screen for dimensions that need further measurement.
- Both total and subscale scores can be calculated and used in economic evaluations and descriptive analyses, respectively.
- Psychometrically robust (demonstrated validity and reliability).
- Results summarised by the WHODAS 2.0 manual¹⁰⁶ and Ustun *et al.* (2010)¹⁰⁵ suggests that the 36-item tool is at least as good as other measures (LHS, SF-36) in detecting change in diverse clinical and geographical populations (schizophrenia (China, Cuba, India, Japan), depression (Nigeria, UK), alcohol dependency (Russia), osteoarthritis (UK), back pain (USA)). Additional studies have also demonstrated that the WHODAS 2.0 (36 item) can detect improvements in a variety of chronic illnesses,¹⁰⁹⁻¹¹¹ and the 12 item version detected changes in symptoms of people with anxiety disorders.¹¹²
- Tool has been widely used and has been applied successfully in several large-scale international population surveys (e.g. World Mental Health Survey (12 item), Global study on Ageing (12 item), WHO/UN Economic and Social Commission for Asia and the Pacific project (36 item))¹⁰⁶
- User manual available free online (WHO)¹⁰⁶ with interviewer, self, and proxy-administered versions.

The subscales of the WHODAS 2.0 measure a range of categories linked mainly to the Activities and Participation (A&P) component of the ICF: understanding and communicating, self-care (ADL), mobility (in/out of home), relationships (friends, family and strangers), participating in life activities (in home, work, school) and participation in society. It is not obvious from the name of the last subscale (Participation in Society) that some of its items relate to **contextual factors** (living

in dignity due to the attitudes of others; barriers and hindrances in the world around you) and the **impact on the family** (e.g. financial drain on family). This subscale could therefore be useful in assessing the wider effects of an intervention on the family/community although it may involve item-level analyses. Note however that these contextual/family impact questions are excluded from this subscale in the 12 item version.

The following tools are contenders with the WHODAS but have some limitations:

2)The ICF Measure of Participation and Activities (IMPACT-S, Post *et al.* 2008¹¹⁵) is a new tool similar to the P-Scale and WHODAS 2.0 except that it has been developed in the Netherlands with no evidence of responsiveness and no cultural adaptations for LMICS - as yet. It asks respondents for the amount of limitations they experience in 9 categories directly linked to the ICF, producing a total score, 2 scale scores (Activities; Participation) and 9 sub-scales (Learning & Applying Knowledge; General Tasks & Demands; Communication; Mobility; Self-care; Domestic Life; Interpersonal Interactions and relationships; Major Life Areas; Community, Social and Civic Life). It may be useful in the future.

3)The Perceived Impact of Problem Profile (PIPP)¹¹⁶ has been developed recently in Australia and Asia to measure not only Activities and Participation, but also Psychological Wellbeing. It asks respondents how much impact their current health problem has had on 23 functions or activities and how distress this has caused. It produces scores of impact and distress on 5 subscales (Self-care, Mobility, Participation, Relationships, Psychological Wellbeing). However, it is not yet widely used, has little evidence of responsiveness, and provides sub-scale scores but no total score. It is freely available for non-commercial use from the author (jpallant@swin.edu.au, Julie Pallant).

The Participation Scale (P-Scale¹¹³), is a psychometrically robust tool of 18 items that has been developed from concept specifically in LMICs to measure participation in all populations, but particularly those with stigmatised conditions (leprosy, HIV/AIDs). It asks respondents whether they experience a particular situation (e.g. *In your home, do you do household work?*) and then probes as to the level of problem if their response suggests that there is one. Some questions ask respondents to compare themselves to peers (e.g. *Do you have the opportunity to take of yourself as well as your peers?*) and then probes further if their answer suggests that there is a discrepancy in their participation compared to peers.

The P-Scale does contain questions about activities such as self-care and moving around the community, but these are very few in comparison to those that measure participation in society (see description under 4.2), and no subscales of are produced to be able to summaries activities or decipher them from the total score representing Participation. It is not recommended as a tool measuring Activities, but Participation.

Table 4.2. Tools measuring Activities in Adults

| Acronym | Concept | Purpose | Items | Dimensions/Subscales | Total/ sub-scale scores | Target popln | Country of origin (Language) | Country adaptations (LMICs) | Content (theory model) | Validity | Reliability | Citations per year |
|---|----------------------------|---|------------------------------|---|--------------------------------|---|------------------------------------|-----------------------------------|--|----------|----------------------------------|-----------------------|
| ACS ¹¹⁷ | Participation | Clinical - consultation & planning intervention | 88 (pictures) | 4 subscales: Instrumental ADL, Social-cultural Activities, low- and high-level physical leisure activities | Y/Y | Generic (50-88 yrs) | USA (Israel ^φ) | Hong Kong, Australia | (++) | (+) | (-) | 1.6 (2003) |
| AAP ¹¹⁸ | Lifestyle activities | Assess activity levels | 24 | 4 subscales: Domestic Chores, household maintenance, service to others, social activities | N/Y | Generic (>70 yrs) | Australia (English) | - | (+) adapted FAI | (++) | (+) Total (-) Sub-scales | 2.4 (1995) |
| CGI-FI ¹¹⁹ | Functional impairment | Method for cross-cultural and sex-specific function assessment | 10 max (8 for men in Rwanda) | 1 scale of items about tasks done for self, family and community. (Tasks are chosen by the local community e.g. In Uganda tasks included dressing, washing, farming, advising the family, participating in burial ceremonies). | Y/N | Generic | Uganda, Rwanda | - | (+) (content different for each country) | (+) | (-) Rwanda; (+) Uganda | 3.9 (2002) |
| IMPACT-S ¹¹⁵ | Activities & Participation | Large-scale epidemiological & outcomes studies | 33 | 2 scales (Activities; Participation) 9 subscales: Learning & Applying Knowledge; General Tasks & Demands; Communication; Mobility; Self-care; Domestic Life; Interpersonal Interactions and relationships; Major Life Areas; Community, Social and Civic Life | Y/Y (Total, Scale, & subscale) | Generic (18 - 70 yrs) | Netherlands (Dutch) | - | ICF | (++) | (++) | n/a (2008) |
| Late Life FDI – Function Component ¹²⁰ | Function (Physical) | assess activity concepts related to upper and lower extremity functioning across a wide variety of daily physical tasks | 32 | 3 subscales: Advanced Lower extremity; Basic Lower Extremity; Upper Extremity | Y/Y | Generic ≥ (60 yrs) | USA (English) | - | (++++) Nagi | (++) | (+) | 5.5 (2002) |
| LIFE-H (Short) ¹²¹⁻¹²² | Social Participation | Screening occurrence of handicap situations | 69 | 12 categories conceptualised as Daily Activities (Nutrition, Fitness, Personal Care, Communication, Residence, Mobility) and Social Roles (Responsibility, Interpersonal relations, Community, Education, Employment, Recreation). | Y/Y | PWDs | Canada (English, French) | - | (++) ICIDH/ DCP | | (++) (Total and subscale scores) | 8.8 (1998) |
| P-scale ¹¹³ | Participation | Evaluate rehab, social inclusion & stigma reduction programmes; assessment of needs & risk of socio- | 18 | No subscales. Items cover following ICF categories: Learning & Applying Knowledge; Communication; Mobility; Self Care; Domestic Life; Interpersonal Interactions and Relationships; | Y/N | Generic (esp. stigmatised conditions e.g. | India, Nepal, Brazil (7 languages) | - | (++) ICF | (++) | (++) | 7 (2006) |

| | | | | | | | | | | | | |
|--|--|--|----|---|-----|--|---|--|------------------------|--|------|---------------|
| | | economic problems; monitoring. | | Major Life Areas; Community, Social and Civic Life. | | HIV/ AIDS leprosy | | | | | | |
| PIPP ¹¹⁶ | Activities & Participation & Psychological Wellbeing | assess impact and distress of health problems | 23 | 2 x 5 subscales (scored on both Impact and Distress): Self-care; Mobility; Participation; Relationships; Psychological Wellbeing | N/Y | Generic | Australia (English); piloted in Thailand & Malaysia | Thailand, Malaysia | (+++) ICF | (++) | (+) | 2.3 (2006) |
| ROPP ¹²³ | Participation | Patient & rehabilitation team use | 22 | Measures Performance and Satisfaction with 9 subscales: Personal Maintenance, Mobility, Exchange Information (communication?), Home Life, Education; Work & Employment; Economic Life; Civic & Community Life | Y/? | Generic (neurological rehabilitation patients) | Sweden (Swedish) | - | (+++) ICF/ ICIDH | (0) assume validity as based on ICF | (++) | n/a (2007) |
| WHODAS 2.0 (Long) ¹⁰⁵⁻¹⁰⁶ | Functioning & Disability | Population Surveys, Registers, monitoring individual patients, clinical trials | 36 | 6 subscales: Communication; Mobility; Self-care; Getting along (with others); Life Activities (domestic, leisure, work school); Participation (in community/society) | Y/Y | Generic (≥ 16 yrs) ψ | 19 (>27 languages countries) including Cambodia, China, Cuba, India, Lebanon, Nigeria, Peru | Dominican Republic, Venezuela, Mexico, | (+++) ICF | (++) | (++) | n/a (2010) |
| WHODAS 2.0 (Short) ¹⁰⁵⁻¹⁰⁶ | Functioning & Disability | Population Surveys, Registers, monitoring individual patients, clinical trials | 12 | 6 subscales: Communication; Mobility; Self-care; Getting along (with others); Life Activities (domestic, leisure, work school); Participation (in community/society) | Y/Y | Generic (≥ 16 yrs) ψ | As above (for 36 item version) | | (+++) ICF | (++) | | n/a (2010) |

ACS = Activity Card Sort; **AAP** = Adelaide Activities Profile; **CGI-FI** = Community-Generated Index of Functional Impairment; **FAI** = Frenchay Activities Index; **IMPACT-S** = ICF Measure of Participation and Activities- Screener; **Late Life FDI** = Late life Function and Disability instrument; **LIFE-H** = Assessment of Life Habits; **P-Scale** = Participation Scale; **PIPP** = Perceived Impact of Problem Profile; **ROPP** = Rating of Perceived Participation; **WHODAS 2.0** = WHO Disability Assessment Schedule 2.0

P-Scale - * Generic from outset, but specifically useful for stigmatised conditions (e.g. leprosy, HIV/AIDS, could be biased towards physical disability)

φ Reviewed from study in Israel as American manual unavailable.

β = The CGI-FI development paper present a *process* by which the content of the tool in each country is generated by a 'free-listing' activity in the community at the start, so tools in Uganda and Rwanda had different content. E.g. Tasks chosen by the local community in Uganda tasks included dressing, washing, farming, advising the family, participating in burial ceremonies

* **WHODAS 2.0** - There is also a 2 part (12+24 item) version of the WHODAS 2.0 (the 12 questions are used as a screening tool); ψ validated with populations with physical/mental/emotional/alcohol/drug abuse problems

4.2. Tools Measuring Participation in Adults

The ICF defines an activity as 'executing a task or action' and participation as 'involvement in a life situation'. As noted above, since ICF categories are combined under 'Activities & Participation' it is sometimes unclear as to what constitutes one or the other and it may depend on the specific wording of a question (e.g. *doing housework such as sweeping versus taking care of household responsibilities*). Nonetheless, it is understood that activities performed among the wider community such as going to work, school, and religious ceremonies constitute 'participation'.

A total of 19 Participation tools were reviewed (Table 4.3). The earliest was developed in 1992 and most (n = 15) were developed using ICF frameworks or its predecessor, the International Classification of Impairments, Disabilities and Handicaps (IDIDH). Those tools that are recommended for measuring participation are:

1) The World Health Organisation Disability Assessment Schedule 2.0

(**WHODAS 2.0**) is the only tool that meets all of the preferred criteria.

- A description of this tool (36 & 12 item versions) and how it meets these criteria is given above (4.1).
- The Life activities subscale asks 8 questions about having difficulties in performing household responsibilities/tasks and work/school. Taking part in community activities (festivities, religious or other activities) is asked in a separate scale called 'Participation in Society'.
- As well as community activities, the 'Participation in Society' subscale contains a wide range of content: problems faced from environmental barriers; living in dignity because of others' attitudes; time spent on the health condition; affected emotionally by health condition; drain on financial resources; family problems; relaxation and pleasure. While all of these items capture important information, it is questionable whether some of these items report directly on societal participation *per se* – although they may be good predictors.

2) The Participation Scale (P-Scale, van Brakel *et al.* 2006¹¹³) is a psychometrically robust tool of 18 items that has also been developed from concept specifically in LMICs to measure participation in all populations, but particularly those with stigmatised conditions (e.g. leprosy, HIV/AIDs). It asks respondents whether they experience a particular situation (e.g. *In your home, do you do household work?*) and then probes as to the level of problem if their response suggests that there is one. Some questions ask respondents to compare themselves to peers (e.g. *Are you as socially active as your peers?*) and then probes further if their answer suggests that there is a discrepancy in their participation compared to peers. Questions cover many aspects of participation, from feeling comfortable in meeting new people, to taking part in major festivals and 'working as hard' as peers. Some questions ask about contextual influences on participation such as *'Do you have as much respect in the community as your peers?'* and *'In family discussions, does your opinion count?'*. A question on economic productivity *'Do you contribute to the household economically in a*

similar way to your peers?’ may provide data that can shed light on household poverty data. The questions appear to be contextually relevant to LMICS.

However as a relatively new tool (2006), it has been less widely used compared to the WHODAS 2.0, has little evidence of responsiveness, and provides only a total score which limits the descriptive evidence on impact. The User Manual is also freely available online,¹¹⁴ or from the author <w.v.brakel@kit.nl>.

The IMPACT-S, PIPP, PM-PAC and IPA are all more recent tools that may prove useful in the future, but currently cannot be recommended over the WHODAS or Participation Scale:

3)The ICF Measure of Participation and Activities (IMPACT-S, Post et al. 2008¹¹⁵) is a new tool similar to the P-Scale and WHODAS 2.0 except that it has been developed in the Netherlands with no evidence of responsiveness and no cultural adaptations for LMICS - as yet. It asks respondents for the amount of limitations they experience in 9 categories directly linked to the ICF, producing a total score, 2 scale scores (Activities; Participation) and 9 sub-scales (Learning & Applying Knowledge; General Tasks & Demands; Communication; Mobility; Self-care; Domestic Life; Interpersonal Interactions and relationships; Major Life Areas; Community, Social and Civic Life). It may be useful in the future.

4)The Perceived Impact of Problem Profile (PIPP)¹¹⁶ has been developed recently in Australia and Asia, to measure not only Activities and Participation but Psychological Wellbeing. It asks respondents how much impact their current health problem has had on 23 functions or activities and how much distress this has caused. It produces score of impact and distress on 5 subscales (Self-care, Mobility, Participation, Relationships, Psychological Wellbeing). However, it is not yet widely used, has little evidence of responsiveness, and provides sub-scale scores but no total score. It is freely available for non-commercial use from the author (jpallant@swin.edu.au, Julie Pallant).

5)The Impact on Autonomy and Participation (IPA, Cardol et al. 1999, 2001¹²⁴⁻¹²⁵) is a 39 item questionnaire asking respondents to rate (from excellent to very poor) ‘how good the possibility of doing X’ is, for example ‘the possibility to spend my income the way I want’. It produces a profile of 5 scales representing Autonomy indoors, Family Role, Autonomy Outdoors, Social Relations, Work and Education, plus 8 single-item scores measuring problems experienced when participating. There is some preliminary evidence of its responsiveness.¹²⁶

Other tools of potential interest:

The Community Integration Measure (CIM) was developed by McColl et al. (2001)¹²⁷ among traumatic brain injury populations but has been applied across other impairment groups. It has been proven to be psychometrically robust. It asks 10 questions specifically about the relationship of the PWD with his or her

community and could be of particular use in comprehensive rehabilitation programmes such as CBR. There is no evidence of responsiveness on the CIM but it may be a practical tool that could be easily adapted to LMICs, reporting on a relevant concept.

The Craig Handicap Assessment & Reporting Technique (CHART/CHART-R)¹²⁸⁻¹²⁹ and the Assessment of Life Habits (LIFE-H (Short))¹²¹: While there are many comprehensive tools of good psychometric properties that have been developed in Europe and North America, the two that have been the most widely used are the CHART/CHART-R and the LIFE-H. The **CHART/CHART-R** would be recommended over the **LIFE-H (Short)** in terms of feasibility and content, having fewer items (≤ 32) and sub-scale on economic self-sufficiency (household income) which is particularly pertinent to LMICs, but would need to be carefully adapted. The questions are also feasible because they are fairly objective, asking about the number of hours the respondent has spent e.g. working, or the number of times they have gone outside the home. The CHART subscales are, however, not recommended by the authors for combining into a total score and so could not be used as the primary outcome in cost-effectiveness analyses.

The original LIFE-H (Long) has 240 items and was therefore excluded from the review. The LIFE-H (Short) provides both subscales and total scores that reflect a very comprehensive combination of both activities (Daily Activities) and participation (Social roles) but still at the cost of time – having 69 items – and the content would require a lot of adaptation as activities mentioned are quite Western-specific (e.g. *Doing indoor physical activities to maintain or improve your physical fitness; crossing traffic-lights*). In accordance with the name 'Life Habits', the questions are also phrased on *doing the activities* required for participating in a life situation (e.g. *carrying out special tasks in relation to your work?*) rather than asking more open questions about participation (e.g. *How much difficulty did you have in your day-today work?* - from WHODAS 2.0)

Despite being around for a long time, neither the LIFE-H nor the CHART/CHART-R has been widely cross-culturally adapted to LMICs (unlike e.g. the SF-36 which was developed around the same time). The CHART has been used in India, Ghana and South Africa, but without any formal adaptation process reported.¹³⁰⁻¹³²

Table 4.3. Tools measuring Participation in Adults

| Acronym | Concept | Purpose | Items | Subscales | Total/ sub-scale scores | Target popln | Country of origin (Language) | Country adaptation s (LMICs) | Content (theory model) | Validit y | Reliabilit y | Citations per year |
|---|----------------------------|--|-------------|---|--------------------------------|-----------------------------------|------------------------------------|-------------------------------------|--|--------------|---------------------------------|-----------------------|
| ACS ¹¹⁷ | Participation | Clinical - consultation & planning intervention | 88 Pictures | 4 subscales: Instrumental ADL, Social-cultural Activities, low- and high-level physical leisure activities | Y/Y | Generic (50-88 yrs) | USA (Israel [Ⓟ]) | Hong Kong, Australia | (++) | (+) | (-) | 1.6 (2003) |
| CGI-FI ¹¹⁹ β | Functional impairment | Method for cross-cultural and sex-specific function assessment | 10 max | 1 scale of items about tasks done for self, family and community ^β (e.g. dressing, washing, farming, advising the family, participating in burial ceremonies) | Y/N | Generic | Uganda, Rwanda ^β | - | (+) | (+) | (-) Rwanda; (+) Uganda | 3.9 (2002) |
| CIM ¹²⁷ | Community Integration | Measure community integration | 10 | None: Items include feeling part of community, accepted by community, doing things for fun in the community, doing something that is useful and productive in the community | Y/N | Generic? ^π (19-76 yrs) | Canada (English) | - | (++) Empiric ally derived theory | (++) | (+) | 5 (2001) |
| CHART ¹²⁸ | Handicap | Measure level of handicap in a community setting | 27 | 5 subscales: Physical Independence, Mobility, Occupation, Social Integration, Economic Self-Sufficiency | ?/Y [†] | Generic (16-74 yrs) | USA (English) | India, Ghana, S.Africa [Ⓛ] | (+) ICIDH | (++) | (+) | 18.4 (1992) |
| CHART (Revised) ^{129, 133} | Handicap | Measure level of handicap in a community setting | 32 | 6 subscales: Physical Independence, Mobility, Occupation, Social Integration, Economic Self-Sufficiency, Cognitive Independence | ?/Y [†] | Generic (16-74 yrs) | USA (English) | - | (+) ICIDH | (+) | (+) | 3.3 (2003) |
| IMPACT-S ¹¹⁵ | Activities & Participation | Large-scale epidemiological & outcomes studies | 33 | 2 scales (Activities; Participation) 9 subscales: Learning & Applying Knowledge; General Tasks & Demands; Communication; Mobility; Self-care; Domestic Life; Interpersonal Interactions and relationships; Major Life Areas; Community, Social and Civic Life | Y/Y (Total, Scale, & subscale) | Generic (18 - 70 yrs) | Nether-lands (Dutch) | - | ICF | (++) | (++) | n/a (2008) |
| IPA ¹²⁴⁻¹²⁶ | Handicap & autonomy | Describe (profile) disease severity assessment, needs assessment, and outcome assessment | 31 + 8 | 5 subscales for perceived participation: Autonomy indoors, Family Role, Autonomy Outdoors, Social Relations, Work and Education; plus 8 single-item scores measuring problems experienced when participating | N/Y | Generic (≥18 yrs) | Nether-lands (Dutch) | - | (+) ICIDH | (++) | (++) | 6 (1999) |
| KAP ¹³⁴ Σ | Participation | Measure the occurrence of participation restriction in populations | 11 | 3 domains (no subscales): Mobility, Domestic Life, Major life | Y/N | Generic (sample > 50 yrs) | England (English) | - | (+++) ICF | (-) | (-) | 3.2 (2005) |

| | | | | | | | | | | | | |
|--|--|--|----|---|------------------|---|---|--------------------|-----------------------|------|---|---------------|
| LHS ¹³⁵⁻¹³⁶ | Handicap | Assess specific therapies & health services in clinical trials, analyses of cost effectiveness, assessments of quality assurance. | 6 | 6 domains (1 item per question): mobility, orientation, physical independence, occupation, social integration, and economic self sufficiency. | Y/N [‡] | Generic (55 - 74 yrs) | England (UK) | China, Nigeria | (++) ICIDH | (+) | (-) | 4.4 (1994) |
| Late Life FDI – Disability Component ¹³⁷ | Disability | assess and be responsive to meaningful change in 2 distinct components (function/disability) | 16 | 2 dimensions with 4 domains: Frequency dimension (Social role; Personal Role); Limitation Dimension (Instrumental Role; Management Role) | N/Y | Generic (≥ 60 yrs) | USA (English) | - | (++++) Nagi | (++) | (+) Dimension scores (-) Domain Scores | 8.1 (2002) |
| LIFE-H (Short) ¹²¹⁻¹²² | Social Participation | Screening occurrence of handicap situations | 69 | 12 categories conceptualised as Daily Activities (Nutrition, Fitness, Personal Care, Communication, Residence, Mobility) and Social Roles (Responsibility, Interpersonal relations, Community, Education, Employment, Recreation). | Y/Y | PWDs | Canada (English, French) | - | (++) ICIDH/ DCP | | (++) (Total and subscale scores) | 8.8 (1998) |
| P-scale ¹¹³ | Participation | Evaluate rehab, social inclusion & stigma reduction programmes; assessment of needs & risk of socio-economic problems; monitoring. | 18 | No subscales. Items cover following ICF categories: Learning & Applying Knowledge; Communication; Mobility; Self Care; Domestic Life; Interpersonal Interactions and Relationships; Major Life Areas; Community, Social and Civic Life. | Y/N | Generic (esp. stigmatised conditions e.g. HIV/AIDS) | India, Nepal, Brazil (7 languages) | - | (++) ICF | (++) | (++) | 7 (2006) |
| PAR-PRO ¹³⁸ | Participation (Home & Community) | Measure participation | 20 | Items include: Work, Education; Volunteering; Housework; Caregiver Activities; Money Management; Shopping; Yard work; Hobbies; Socializing; Movies; Spiritual Activities; Transportation; Driving; Intimate Relationships | Y/N | Generic (19 - 99 yrs) | USA (English) | - | (+++) ICF | (+) | (+) | 2.5 (2006) |
| PIPP ¹¹⁶ | Activities & Participation & Psychological Wellbeing | assess impact and distress of health problems | 23 | 2 x 5 subscales (scored on both Impact and Distress): Self-care; Mobility; Participation; Relationships; Psychological Wellbeing | N/Y | Generic | Australia; piloted in Thailand & Malaysia | Thailand, Malaysia | (+++) ICF | (++) | (+) | 2.3 (2006) |
| PM-PAC ¹³⁹ | Participation | Measure participation outcomes of rehabilitation services in outpatient or home-care settings. | 51 | 9: Mobility; Role functioning; Work; Education; Economic life; Domestic life; Community, Social, and Civic life; Interpersonal relationships; and Communication. | ?/Y | Generic (≥18) | USA (English) | - | (+++) ICF | (++) | (++) | 5.7 (2007) |

| | | | | | | | | | | | | |
|--|--------------------------|---|----|--|-----|--|---|---|------------------------|----------------------------------|--------------------------|------------|
| POPS ¹⁴⁰ | Participation | Evaluate Rehabilitation (group level) and potentially individualised measurements in clinic | 26 | 2 x 5 subscales: Measure objective (performance) and subjective (satisfaction in) participation in 5 subscales: Domestic Life; Interpersonal Interactions and Relationships; Major Life Areas; Transportation; and Community, Recreational and Civic Life. | Y/Y | Generic? € | USA (English) | - | (++) ICF | (+) | (+) Total; (-) Sub-scale | 5.3 (2004) |
| ROPP ¹²³ | Participation | Patient & rehabilitation team use | 22 | Performance & Satisfaction with 9 subscales: Personal Maintenance, Mobility, Exchange Information, Home Life, Education; Work & Employment; Economic Life; Civic & Community Life | Y/? | Generic (neurological rehabilitation patients) | Sweden (Swedish) | - | (+++) ICF/ ICIDH | (0) assume valid as based on ICF | (++) | n/a (2007) |
| WHODAS 2.0 (Long) ¹⁰⁵⁻¹⁰⁶ | Functioning & Disability | Population Surveys, Registers, monitoring individual patients, clinical trials | 36 | 6 subscales: Communication; Mobility; Self-care; Getting along (with others); Life Activities (domestic, leisure, work school); Participation (in community/society) | Y/Y | Generic (≥ 16 yrs) | 19 (>27 languages) incl. Cambodia, China, Cuba, India, Lebanon, Nigeria, Peru | | (+++) ICF | (++) | (++) | n/a (2010) |
| WHODAS 2.0 (Short) ¹⁰⁵⁻¹⁰⁶ | Functioning & Disability | Population Surveys, Registers, monitoring individual patients, clinical trials | 12 | 6 subscales: Communication; Mobility; Self-care; Getting along (with others); Life Activities (domestic, leisure, work school); Participation (in community/society) | Y/Y | Generic (≥ 16 yrs) | As above (for 36 item version) | | (+++) ICF | (++) | | n/a (2010) |

ACS = Activity Card Sort; **AAP** = Adelaide Activities Profile; **BDQ** = Brief Disability Questionnaire; **CGI-FI** = Community-Generated Index of Functional Impairment; **CIM** = Community Integration Measure; **CHART** = Craig Handicap Assessment and Reporting Technique; **FAI** = Frenchay Activities Index; **IMPACT-S** = ICF Measure of Participation and Activities- Screener; **IPA** = Impact on Participation and Autonomy; **KAP** = Keele Assessment of Participation; **LHS** = London Handicap Scale; **LIFE-H** = Assessment of Life Habits; **PM-PAC** = Participation Measure- Post Acute Care; **POPS** = Participation Objective Participation Subjective; **P-Scale** = Participation Scale; **PIPP** = Perceived Impact of Problem Profile; **ROPP** = Rating of Perceived Participation; **WHODAS 2.0** = WHO Disability Assessment Schedule 2.0

P-Scale - * Generic from outset, useful for stigmatised conditions (e.g. leprosy, HIV/AIDS)

[✳] **WHODAS 2.0** - There is also a 2 part 26 item (12+24) version of the WHODAS 2.0 (the 12 questions are used as a screening tool)

β = The CGI-FI development paper present a *process* by which the content of the tool in each country is generated by a 'free-listing' activity in the community at the start, so tools in Uganda and Rwanda had different content. E.g. Tasks chosen by the local community in Uganda tasks included dressing, washing, farming, advising the family, participating in burial ceremonies

ϕ Reviewed from study in Israel as American manual unavailable.

† A total CHART score can be calculated but authors recommend using the subscale scores, as total score can be misleading.

‡ Total score is part utilities/measure of severity (of disadvantage) between 0 and 1

€ POPS is adapted from TBI research instrument (Adapted the Living Life After Traumatic Brain Injury), and tested in TBI patients

¶ CIM was conceptualised around people with brain injuries; used with 'clients with various disability types', and used in stoke, but mostly brain injury.

⊙ CHART was applied without adaptation to children in S. Africa

∑ KAP questions ask about participating 'as and when you wanted' (nature and timeliness) rather than difficulty in participation. The authors highlighted limitations (e.g. reliability) and concluded that further testing and revisions are needed.

4.3. Tools measuring Quality of Life, Health Status and related concepts in Adults

A total of 17 tools were reviewed that reported to measure QOL and related concepts such as health related quality of life (HRQOL), health status, and wellbeing (Table 4.4). There are definitions that attempt to distinguish each concept.¹⁴¹ However, these terms are often used interchangeably in practice.¹⁴² For example, the Quality of Wellbeing Scale¹⁴³⁻¹⁴⁴ is reported at different stages of development to measure wellness, wellbeing, and HRQOL, despite the fact that it actually has no content representing one of the key dimensions of health¹⁴⁵ – mental health. The Health Utility Index instruments¹⁴⁶⁻¹⁴⁷ are reported to measure health status and HRQOL, yet they do not include any content on another aspect of health¹⁴⁵ – social functioning. While tools may appear to measure similar concepts it is important (as with Activity/Participation tools) to select tools based on a closer look at the content to ensure that they are truly comprehensive and/or complement data collected by other tools.

There are 3 tools that we recommend to use to assess QOL in impact assessment. These tools are all highly cited and available in LMICs, and meet most the preferred criteria. They are the WHOQOL instruments (WHOQOL-BREF & WHOQOL-DIS), and the Medical Outcomes Study Short-Form instruments (SF-36 and SF-12).

1) **The WHOQOL-BREF** (WHOQOL Group, 1998¹⁴⁸) is a shortened version of the original 100 item WHOQOL instrument. Both tools have good applicability in LMICs as they were developed simultaneously from concept across 14-18 countries including LMICS in Africa, Asia and Latin America. The content goes beyond health-related QOL to represent broader dimensions of QOL relevant to the environment such as safety, services and finances.

The WHOQOL-BREF asks respondents 26 questions how much (frequency) they have experienced and/or were able to do things (e.g. feel safe, able to concentrate, enjoy life) in the past 4 weeks and how satisfied they are with certain aspects of their lives (e.g. sleep, sex life, capacity for work). Although the WHOQOL-BREF is shorter than the original version it is still comprehensive, containing all 24 facets of the original questionnaire and producing 4 subscales: Physical Health, Psychological Health, Social Relationships, and Environment.

Since the development of the WHOQOL-BREF, many papers have confirmed robust psychometric properties.¹⁴⁹⁻¹⁵² There are fewer data on the responsiveness of the WHOQOL-BREF when evaluating the impact of interventions; however existing evidence is encouraging.^{149, 153-154} For example, there were significant improvements in all 4 subscales in depressed outpatients

12 weeks after antidepressant treatment, consistent with reductions in the severity of depressive symptoms.¹⁵³ Similarly, there was significant improvement in 3 out of 4 domains after surgical interventions for cervical spondylotic myelopathy¹⁵⁴ and total hip/knee replacement,¹⁵⁰ respectively. The WHOQOL-BREF was reported to be less responsive than the SF-36 in the former study.¹⁵⁴ Significant improvements were detected in 2 subscales after intervention in trachoma patients - despite no improvement in visual acuity - supporting that clinical outcomes are not always indicative of impact on CCOs.¹⁵⁵

In addition, an add-on module developed and validated for people with a diverse range of disabilities has just been published (**WHOQOL-DIS**), with preliminary evidence of good psychometric properties.¹⁵⁶ The WHOQOL-DIS is predominantly focused on the impact of environmental factors on QOL, producing a single score, and may therefore be useful in evaluating non-medical interventions. Evidence on responsiveness is still to come.

The **WHOQOL-OLD** has been developed as an add-on module to address limitations in the WHOQOL-BREF for application with elderly populations.¹⁵¹

The main limitation of the WHOQOL-BREF for evaluating impact is that the original development papers and scoring manual does not provide methods for calculating a total score, limiting its application in economic evaluations. However, some studies have calculated a total score.^{153, 157} Nor can the WHOQOL-DIS and the WHOQOL-BREF be combined into a single score. Nonetheless, the WHOQOL-BREF provides a comprehensive tool for describing the impact of impairment and rehabilitation. The user manual is also freely available from the WHO website with methods for carrying out translations/cross-cultural adaptations which must be followed.

- 2) **The SF-36** was developed by Ware and colleagues¹⁵⁸⁻¹⁶⁰ for the RAND Corporation in the USA and is judged to be the most widely used instrument measuring health status worldwide.¹⁶¹ This is evident from the number of citations per (538) year exceeding that of any other instrument in the Tables 4.2, 4.3 and 4.4 by many-fold.

The SF-36 asks respondents 36 questions, mainly about the extent to which their health or emotional problems have limited or interfered with their normal activities, as well as the frequency with which they felt certain emotions (e.g. sad and blue). Two summary scores (Physical and Mental Health) and 8 subscales can be calculated (Physical functioning, Role Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role Emotional, Mental Health).

The potential benefits of the SF-36 for evaluating rehabilitation for PWDs are:

- Comparability of results with many other studies
- The concept measured by the SF-36 (health status) includes mental, physical and social functioning and 8 subscales and 2 summary scores (Physical and Mental Components). This is narrower than the broad QOL concept measured by the WHOQOL, but it may offer information which complements (rather than overlaps with) content of Activities/Participation/Disability tools being used.
- A shorter version (**SF-12**) is available with evidence of good psychometric properties, that could be used to measure Mental and Physical components (not subscales). This may be more practical for some studies where a lot of other information is being collected as well
- A preference-based total score can be calculated from any SF-36 data set (the SF-6D, used to calculate utilities and can therefore be used to assess QALYS gained in CUAs), however the appropriateness of measuring health status in LMICs from Utility Values generated in the UK/USA is questionable (see below for a fuller explanation).

The limitations of the SF-36 are that it does not produce a total summed score from the 8 subscales or 2 summary scales that is non preference-based (i.e. other than a utility value). PWDs may not identify their impairment as a 'health problem'. It would also need some adaptation for use with PWDs as there are 5 questions asking about climbing and walking, which has proven problematic when administered to people with mobility impairments¹⁶².

The original SF-36 (version 1, called the RAND 36-item Health Survey) is freely available from RAND (http://www.rand.org/health/surveys_tools/mos/mos_core_36item.html). The version known as the SF-36 Health Survey and the revised version (SF-36v2) with better wording, response options, and psychometric properties, together with the SF-12, are copyrighted by the Medical Outcomes Trust. Licences for use (unless it is non-funded research) must be purchased from Qualitymetric (<http://www.sf-36.org/>).

Table 4.4. shows a number of other popular tools producing total scores. For example, the **EQ-5D** is short and simple and the **HUI Mark II/III** has content of relevance to PWDs such as Vision, Hearing, Speech, Ambulation. Unfortunately, these tools produce a preference-based total score (utility value), for which sets of preference values derived from populations in LMICS do not exist (with the rare exception e.g. an EQ-5D value set for Zimbabwe). Therefore their use in LMICs is questionable. Moreover, the EQ-5D and the HUI

have both been criticised - the EQ-5D for being quite crude as it only asks 5 questions and only allows 3 response options which therefore restricts its sensitivity when trying to detect change. The newly published child-version (EQ-5D-Y, also with 3 level response options) has similar problems, and the developers of EQ-5D are now developing a version with a 5 level response scale as a result.¹⁶⁴ The HUI Mark II/III has also been criticised for the absence of any questions on social functioning and the weak representation of mental health.

Table 4.4. Tools measuring Quality of Life, Health Status and related concepts for Adults

| Acronym Σ | Concept | Purpose | Items | Subscales | Total/ sub-scale scores | Target popln | Country of origin (Language) | Country adaptations (LMICs) | Content (theory model) | Validit y | Reliabilit y | Citations per year |
|--------------------------------|---------------------------------|--|-------|---|-------------------------------|---|---|--|------------------------------|--------------|-----------------------|-----------------------|
| <u>EQ-5D</u> | HRQOL/ Health Status | Describe and value HRQOL (preference- based) | 5 | None. Content/attributes are: Mobility, Self-care, Usual Activity, Pain/discomfort, Anxiety/Depression | Y/N | Generic | 5 countries in Europe | ≥ 25 Asia, Africa, L. America Ж | (+) | (+) | (0) | 14.2 (2003) |
| EUROHIS- QOL ¹⁶⁵ | QOL | multinational projects on population health, epidemiology, cross- cultural and clinical studies | 8 | None, but items from Psychological, Physical, Social and Environmental domains of the WHOQOL instrument included | Y/N | Generic (≥ 36 years) | 10 countries (9 European + 1 Israel) | - | (++++) ◊ | (++) | (0) | 1.8 (2006) |
| PWI ¹⁶⁶ | Subjective QOL/ Wellbeing | cross-cultural measurement of SWB; identification of support needs and as an outcome measure | 7-8 | 7/8 subscales: Standard of Living, Personal Health, Achievement in Life, Personal Relationships, Personal Safety, Community Connectedness, Future Security, Spirituality (added after first development). | Y/Y | Generic ≥ 18yrs | Australia (English); Hong Kong (Cantonese) | Arabic, Argentina, Mandarin, Israel, Malaysia, Mexico, Persia, Brazil, Tibet | (++) | (+) | (+) Total score | 3.4 (2005) |
| PWI-ID ¹⁶⁷ | Subjective QOL/ Wellbeing | Cross-cultural measurement of SWB; identification of support needs and as an outcome measure | 7-8 | 7-8 subscales: Standard of Living, Personal Health, Achievement in Life, Personal Relationships, Personal Safety, Community Connectedness, Future Security, Spirituality | Y/Y | People with intellectu al disability ≥ 18yrs | Australia (English) | Brazil, China | (0) | (+) | (-) | n/a (2009) |
| QOLS ¹⁶⁸ | QOL | Gather quantitative QOL information from diverse groups with chronic illness | 16 | 6: Material & Physical Wellbeing, Relationships; Social, Community & Civic Activities; Personal Development & Fulfilment; Recreation; Independence | Y/N | Generic (Chronic Illness) | USA (English) | Brazil, Chinese, Farsi, Hebrew, Mandarin Mexico, Thai | (+) | (+++) | (++) | 2 (2003) |
| SF-36 ¹⁵⁸⁻¹⁶⁰ | Health Status | Comparing populations, estimating burden of disease, screening, differentiating health benefits | 36 | 2 Summary Scales: Mental Component and Physical Component; 8 Subscales: Physical Functioning; Role Physical; Bodily Pain; General Health; Vitality; Social Functioning; Role Emotional; Mental Health | N/Y | Generic (≥14yrs) | USA (English) | ≥ 35 Asia, Africa, L. America Б | (++) | (+++) | (+) | 538 (1992) |
| SF-12 ¹⁶⁹ | Health Status | Reproduce sf-36 MCS and PCS scores when monitoring health of | 12 | 2 Summary Scales: Mental Component and Physical Component | N/Y | Generic (≥14yrs) | USA (English) | ≥ 25 Asia, Africa, L. America Ф | (++) | (+++) | (++) | 177 (1996) |

| | | | | | | | | | | | | |
|----------------------------------|----------------------------------|---|-----|--|--|---------------------------------------|--|--|--------|-------|-----------------------------|-------------|
| | | general and specific populations (large sample sizes) | | | | | | | | | | |
| SF-6D ¹⁷⁰ | HRQOL Utility Values | Economic evaluations | 11 | None. 6 dimensions: Physical Functioning; Role Limitations; Pain; Vitality; Social Functioning; Mental Health | Y/N | Generic (≥14yrs) | UK (English) | | (++) | (0) | (+) | 59.9 (2002) |
| NHP ¹⁷¹ | Perceived health problems/HRQOOL | Population health surveys, outcome evaluation, clinical evaluation | 38 | 13 subscales: Part 1 (health problems): Sleep; Physical Mobility; Energy; Pain; Emotional Reactions; Social Isolation; Part 2 (Areas of life affected by health): Paid Employment; Jobs around the House; Social Life; Personal Relationships; Sex Life; Hobbies and Interests; Holidays. | N/Y | Generic (≥ 20 yrs) | England (English) | | (++) | (+) | (-) inadequate methods used | 17.6 (1985) |
| WHOQOL – 100 ^{51, 172} | Quality of Life | Comprehensive assessment to improve doctor-patient relationship; evaluate interventions | 100 | 6 domains (with 24 sub-domains/facets and 25th facet on overall QOL): Physical Health (pain, energy, sleep, mobility, activities, medication, work); Psychological Health (positive/negative feelings, think, esteem, body); Social Relationships (relationships, support, sex); Environment (safety, home, finances, services, information, leisure, environment, transport). | N/Y § | Generic (adults - culturally defined) | Across 14 countries including India, Israel, Japan, Panama, Thailand, Zimbabwe | Argentina, Brazil, China, Hong Kong, Israel, India, Korea, Malaysia, Pakistan, Thailand, Zambia, Zimbabwe | (++++) | (++) | (++) | 32.5 (1998) |
| WHOQOL -BREF ^{148, 173} | Quality of Life | Large epidemiological studies and clinical trials, clinical practice | 26 | 4 domains with the same 24 sub-domains (+1 overall QOL facet) of the WHOQOL-100: Physical Health Psychological Health, Social Relationships, Environment | N/Y (4 domain scores only) - No total scores | Generic (adults - culturally defined) | Across 18 countries including India, Israel, Panama, Thailand, Zimbabwe | Argentina, Bangladesh, Brazil, Chile, China, Ethiopia, India, Indonesia, Iran, Jamaica, Korea, Malaysia, Nigeria, Palestine, Rwanda, Sudan, Thailand | (++++) | (+++) | (+) | 45.8 (1998) |

| | | | | | | | | | | | | |
|----------------------------|----------------------------------|---|--------------------------------|--|--|--|--|---|------|-------|------|----------------|
| WHOQOL -OLD 174-175 | Quality of Life | not stated | 24 | 6 subscales: Sensory Abilities; Autonomy; Past, Present and Future Activities; Social Participation; Death and Dying; Intimacy | Y/Y | Older Adults (≥ 60 yrs) | Across 21 countries including China, Israel, Brazil, Uruguay. | - | (++) | (++) | (++) | 8.4 (2005) |
| WHOQOL -DIS 156, 176 | Quality of Life | Studies of population epidemiology, service development, clinical intervention trials; impact of health and social care service provision | 13 | Uni-dimensional (items include: Discrimination, Advocacy, Future, Control, Choice, Autonomy, Communication, Acceptance, Respect, Interaction, Inclusion, Potential) | Y/N | Adults with Intellectual or Physical Disabilities (Field Test incl. MS, Park, VI & HI, Stroke) | 15 countries (most in Europe) including China, Brazil, Uruguay | - | (++) | (++) | (+) | n/a (2010) |
| SIP ¹⁷⁷ | Perceived Health Status | measure outcomes of healthcare for evaluation, programme planning, policy formulation | 136 | 2 Dimensions (Physical, Psychosocial) and 12 scales (7/12 scales combine to form Domains): Sleep & rest; Eat; Work; Home Management; Recreation & Pastimes; Ambulation; Mobility; Body Care & Movement; Social Interaction; Alertness Behaviour; Emotional Behaviour; Communication) | Y/Y/Y (total, domain and scale scores) | Generic | USA (English) | India, Korea, Mexico, Thailand | (++) | (++) | (+) | 90.5 (1981) |
| SIP (68) 178-180 | Health-related functional status | Rehabilitation medicine outcome research (Post et al. 1996) | 68 | 6 subscales: Somatic Autonomy (dressing, standing, walking, eating); Mobility Control (walking & hand/arm control); Mobility Range (shopping/house cleaning, business affairs); Social Behaviour (sex, visiting friend, group activities); Emotional Stability (irritability, acting disagreeably); and Psychic Autonomy/Communication | Y/Y | Generic (18 - 65 yrs) | The Netherlands (Dutch) | | (++) | (+++) | (++) | 5.4 (1994) |
| QWB 143-144 ‡ | HRQOL / Wellbeing | CUAs | 3 (activities) + 36 (symptoms) | 3 functional scales: Mobility (driving, using transport, at home/special care unit); Physical Activity (walking, walking with limitations, moving on wheelchair, in bed/chair); Social activity (self-care, work, school, housework) PLUS Symptoms & Problems | Y/N | Generic | USA (English) | Brazil, China, Korea, Trinidad, Tobago, | (++) | (+) | (0) | 12.9 (1976) |
| HUI | HRQOL/ | Describe health | 8 | None. Content/attributes are: | Y/Y | Generic | Canada | Argentina, | (+) | (+) | (+) | 19 |

| | | | | | | | | | | | | |
|---------------------------------|---------------|---|--|--|--|--|-------------------|--|--|--|--|--------|
| <u>Mark III</u> 146-147, 181 | Health Status | status, Population health surveys, clinical studies, CUAs | | Vision, Hearing, Speech, Ambulation, Dexterity, Emotion, Cognition, Pain | | | (French, English) | China, Brazil, China, Cuba, Korea, Mexico, S. Africa, Singapore, Thailand, Honduras, Colombia, Uruguay | | | | (1995) |
|---------------------------------|---------------|---|--|--|--|--|-------------------|--|--|--|--|--------|

CUA = Cost-utility analyses; **EQ-5D** = Euroqol EQ5D; **HI** = Hearing Impairment; **HUI** = Health Utilities Index; **PWI** = Personal Wellbeing Index (previously ComQOL); **PWI-ID** = Personal Wellbeing Index Intellectual Disability Scale; **QOLS** = Quality of Life Scale; **SF-36** = MOS Short-Form (36 item); **SF-12** = MOS Short-Form (12 item); **SF-6D** = MOS Short-Form (6 item); **MS** = Multiple Sclerosis; **NHP** = Nottingham Health Profile; **Park** = Parkinson’s disease; **WHO** = World Health Organisation; **WHOQOL-100** = WHO Quality of Life (100 item); **WHOQOL-BREF** = WHO Quality of Life (26 item); **WHOQOL-OLD** = WHO Quality of Life for Older Adults; **WHOQOL-DIS** = WHOQOL Disabilities Module; **SIP** = Sickness Impact Profile; **SIP(68)** = Sickness Impact Profile 68; **QWB** =Quality of Wellbeing Scale; **VI** = Visual Impairment

∑ Tools whose names are underlined produce single summary scores that are preference values/weights that can be used to calculate QALYs for CEAs

P-Scale - * Generic from outset, useful for stigmatised conditions (e.g. leprosy, HIV/AIDS)

* **EQ-5D available for:** Argentina, Brazil, China, Chile, Colombia, Costa-Rica, Dominican Republic, Ecuador, Guatemala, India, Indonesia, Israel, Jordan, Lebanon, Malaysia, Mexico, Peru, Pakistan, Panama, Philippines, Puerto Rico, Singapore, South Africa, Thailand, Uruguay, Vietnamese, Venezuela, Zimbabwe

β **SF-36 available for:** Argentina, Brazil, Chile, China, Colombia, Costa-Rica, Ethiopia, Guatemala, Honduras, India, Indonesia, Israel, Jordan, Kenya, Pakistan, Philippines, Malaysia, Mexico, Nigeria, Nicaragua, Pakistan, Palestine, Panama, Paraguay, Peru, Puerto Rico, Singapore, South Africa, South Korea, Tanzania, Taiwan, Thailand, Uganda, Uruguay, Venezuela

ϕ **SF-12 available for:** Argentina, Brazil, Chile, China, Colombia, Ghana, Guatemala, Honduras, India, Indonesia, Israel, Malaysia, Mexico, Pakistan, Palestine, Panama, Paraguay, Peru, Philippines, Puerto Rico, Singapore, South Africa, South Korea, Taiwan, Thailand, Uruguay, Vietnam, Zimbabwe

§ **WHOQOL-100** has 6 domains and 25 sub-domains (called facet) scores. The 6 scales are not scaled in the same direction so summing them is not recommended in the manual.

◇ **EUROHIS QOL** = developed from the WHOQOL-100/BREF

‡**QWB** – A 71 item self-administered version was later published but is not reviewed here as it was not shortlisted to be recommended based on its purpose and content

¶ **SF-12** A there were limited tests of reliability in the original papers but this tool was of interest for recommendations, further evidence¹⁸²⁻¹⁸⁷ was sought that used acceptable methods

4.4. Tools measuring Activities and Participation in Children

There were only 7 tools identified that were conceptualised around measuring activities and/or participation in children. As almost all cover both individual activities (e.g. self-care) and participation (e.g. social, play, education), they are presented and analysed together (Table 4.5)

None of these tools stand out as being superior in terms of development and/or availability for LMICs, nor in terms of wide use - except for the PEDI which is too long (≥ 187 questions) to be of practical use. Many of the tools have been developed within the last 3 years with little or no evidence of responsiveness or successful application in impact evaluations. Few of the tools cover wide age ranges, and all would require significant cross-cultural adaptation to LMICs. However, the following tools may be worthwhile adapting for LMICs:

- The **Assessment of Life Habits for Children (LIFE-H¹⁸⁸)** is a 54 item questionnaire providing a comprehensive profile of 11 subscales of Daily activities (including e.g. self-care, mobility) and Social Roles in major life areas (e.g. Recreation, Education). The questions ask about the level of difficulty and assistance needed. It has been used successfully in cross sectional comparative studies with children with cerebral palsy.¹⁸⁹⁻¹⁹⁰ The drawbacks are that there is no summary/total score, and the time required.
- The **Child and Adolescent Scale of Participation (CASP¹⁹¹)** asks parents to report on the extent of children's participation and restriction in the home, school and community as compared to non-disabled peers of the same age. It is perhaps the most practical of all the tools, having relatively few items ($n = 20$) and being applicable for a wide age range (3-22 yrs). However, it is a new tool with further evidence needed on scoring (e.g. subscales) and psychometrics - including responsiveness.

The following tools are not recommended for reasons explained below:

- The **Pediatric Evaluation of Disability Inventory (PEDI¹⁹³⁻¹⁹⁵)** has been used in research with young children (0.5-7 yrs) with disabilities. It is the only tool applicable to infants and toddlers. It claims to be a functional assessment tool but the content of questions that are asked about self-care (e.g. bladder management) and Mobility (e.g. bed transfer) come under ICF categories of A&P. The phrasing of questions is unclear as it is published only in a manual that can be bought online for \$122 (<http://www.pearsonassessments.com>). However, the length of the tool (≥ 187 items) prohibits use in all but a few research studies.

- The **CHORES (Children Helping Out: Responsibilities, Expectations, and Supports¹⁹⁶)** focuses quite narrowly on participation in children aged 6-11 years old within the household, both on managing tasks related to one's own needs, belongings or space (Self Care), or caring for that of others within the household (Family care). While this is relevant to families in LMICs, its scope is perhaps too narrow to be worthwhile adapting. It does not cover participation in major life areas such as education and recreation/play.
- The **Child Participation Questionnaire (CPQ¹⁹⁷)** is a 44 item questionnaire that has been recently developed and as such there is little evidence on reliability and is applicable for a narrow age range (4-6 yrs).
- The **Generic Lifestyle Assessment Questionnaire (LAQ-G¹⁹⁸)** summarises the impact of disability on both the child and family members in 6 subscales, with no total score. It is quite long (46 items) and the age range is narrow (5-7yrs). Further evidence of psychometrics and responsiveness is needed.
- The **Child Assessment of Participation and Enjoyment (CAPE)**, and the **Preferences for Activities of Children (PAC)¹⁹²** are complementary scales that provide summary score for 6 dimensions of participation (Diversity, Intensity, Where, Whom, Enjoyment and Preferences) covering 5 types of activities (Recreational, Active Physical, Social, Skill-based, Self-Improvement). It is relatively long (55 items) and may be unnecessarily overly-burdensome to elicit all 6 dimensions.

In summary, there is no obvious candidate of childhood A&P to recommend for cross-cultural adaptation to LMICs. The selection of tools measuring QOL and related concepts in children is better than for A&P, and we recommend that readers may want to select appropriate CCO tool(s) for CWDs from section 4.5.

Table 4.5. Tools measuring Activities and/or Participation in Children

| Acronym Σ | Concept | Purpose | Items | Rater | Subscales | Total/ sub-scale scores | Target popln (years) | Country of origin (Language) | Country adaptatio ns (LMICs) | Content | Validity | Reliability | Citations per year |
|------------------------------------|--|---|-------|--------------------------|---|-------------------------------|---------------------------------------|------------------------------------|--------------------------------------|--------------|----------|--------------|-----------------------|
| PEDI ¹⁹³⁻¹⁹⁵ | Functioning | Functional assessment | ≥187 | Parent Clinician | 3: Self care, Mobility; Social Function | Y/Y | Generic (0.5-7) | Canada (English) | Brazil, China, Puerto- Rico | (0) | (+) | (+) | 5.6 (1990) |
| CASP ¹⁹¹ | Participation | Intervention needs, effects, programme improvement and policies | 20 | Parent | Content: General tasks and demands, Communication; Mobility; Self-care; Domestic life; Interpersonal interactions & relationships; Major life areas; Community, social and civic life. | Y/? | Generic (3-22) | USA (English) | - | (+++) ICF | (+) | (+) Total | n/a (2009) |
| CPQ ¹⁹⁷ | Participation | Setting goals, implement treatment programmes, evaluate interventions | 44 | Parent | Measures 5 dimensions of participation (Diversity; Intensity; Independence; Enjoyment; Parent Satisfaction) in 6 activities: 6: ADL, IADL, Play, leisure, social participation, Education | Y/Y | Generic (4-6) | Israel | - | (++) | (+) | (-) | n/a (2010) |
| LIFE-H for Children ¹⁹⁹ | Social Participation | Design research or service implementation | 64 | Parent | 11 subscales; 6 on Daily activities (Communication, Personal Care, Housing, Mobility, Nutrition, Fitness); 5 on Social Roles : (Recreation, Responsibility, Education, Community Life, Interpersonal Relationships) | N/Y | CWDs (5-13yrs) (any impairment) | Canada (English) | - | (++) | (+) | (+) | n/a (2007) |
| CHORES ¹⁹⁶ | Participation in Household Tasks | Clinical and research tool | 33 | Parent | Measures Performance and Assistance for Self Care and Family Care | Y/Y | Generic (6-11) | USA (English) | - | (++) | (+) | (++) | NR (2002) |
| CAPE and PAC ¹⁹² | Participation | information for the design and implementation of interventions | 55 | Self Self with Parent | Measures 6 dimensions (diversity, intensity, where, with whom, enjoyment, preferences) for formal and informal activities, and 5 types of activities: Recreational, Active Physical, Social, Skill-based, Self-Improvement Activities | Y/Y | Generic (6-21) | Canada (English) | - | (++) | (++) | (+) Δ | n/a (2007) |
| LAQ-G ¹⁹⁸ | Participation of children and their families | Information on impact of disability for registers, epidemiological & clinical use | 46 | Parent | 6: Communication, Mobility, Self care, Domestic life, Interpersonal Interactions and Relationships and Community and Social Life | N/Y | Generic (5-7) | UK (English) | - | (+++) ICF | (+) | (0) | 1.9 (2003) |

LAQ-G = Generic Lifestyle Assessment questionnaire; **LIFE-H** = Assessment of Life Habits; **CAPE** = Children’s Assessment of Participation and Enjoyment; **CASP** = Child and Adolescent Scale of Participation; **CHORES** = Children Helping Out: Responsibilities, Expectations, and Supports; **CPQ** = Child Participation Questionnaire; **NR** = Not reported; **PAC** = Preferences for Activities of Children; **PEDI** = Pediatric Evaluation of Disability Inventory
Δ CAPE & PAC – Empirical evidence of reliability was not presented, but summarised for user manual

4.5. Tools measuring Quality of Life, Health Status and related concepts in Children

There were 43 tools measuring QOL, HRQOL health status and related concepts in children aged 0-18 years. Table 4.6 (below) presents all tools in order of the youngest age with which they can be used.

While there are many tools available, only 3 have been developed in LMICs and the latter have not been widely used. For example, the C-QOL²⁰⁰ was developed in Thailand from the WHOQOL-100 (for adults) and similarly encompasses broad dimensions of QOL including rights and citizenship. Applying the tool to look at the determinants of QOL, the developers did not detect any significant impact of chronic, acute nor severe illness on QOL.²⁰¹ It has not been used in empirical research since.

Of those tools that have been developed in high-income countries, very few have been used widely in LMICS, with the exception of the PedsQL, HUI Mark II, and the CHQ. Of these, the HUI Mark II is not recommended for use in LMICS because it is a health status classification system stemming from a tool (HUI Mark I) developed for paediatric cancer populations. Its content (e.g. fertility) still reflects this specific population while omitting social functioning and being limited on mental health content. The dimension of 'Ambulation' rates people according to whether they can walk without assistance rather than move (e.g. by wheelchair), and so would be insensitive to environmental interventions. The total score is based on valuations of health states by populations in high-income countries (i.e. preferences).

Below are the tools we recommend for measuring QOL, HRQOL health status and related concepts in children:

1) The **Pediatric Quality of Life Inventory 4.0 Generic Core (PedsQL)** is a 23 item measure asking '*How much of a problem has X been for you/your child in the past 1 month?*'. It is recommended because:

- It is short and simple (23 items)
- It covers the main dimensions of health and participation (Physical Functioning, Emotional Functioning, Social Functioning, School Functioning). Social functioning includes the impact of others' behaviours on HRQOL (e.g. being teased).
- Age-appropriate versions are available for children with a broad age range (2-18 yrs), by self and proxy report.
- It can be used both as a descriptive profile and in economic evaluations. It produces 4 Subscale Scores (Physical/Emotional/Social/School Functioning), 2 Summary Scales (Psychosocial and Physical Health), and a Total Scale Score.

- It has the highest number of citations per year of all the tools, and has been translated and/or used in at least 15 LMICS.
- It's scales have demonstrated to be responsive to clinical change in children with leg-length discrepancy,²⁰² low-limb deformities,²⁰³ asthma,²⁰⁴⁻²⁰⁵ and rheumatology conditions.²⁰⁶ It was more responsive to change than the CHQ or HUI in children undergoing chemotherapy.²⁰⁷
- The PedsQL offers add-on modules that can be used with the generic core questionnaire, including disease-specific modules relevant to childhood disability (e.g. for Cerebral Palsy) as well as a Family Impact module that measure the HRQOL of parents and family functioning.²⁰⁸⁻²⁰⁹

Use of the PedsQL instruments is free for non-funded academic research. Academic research funded by governments, the European Union or registered charities requires a licence costing \$720 per study plus \$200 per each additional module. See <http://www.pedsqol.org/index.html>.

A limitation of the PedsQL is that it cannot be used for infants and toddlers below the age of 2 years.

2) **The Functional Status (II)** (FS II(R), Stein & Jessop, 1990²¹⁰) can be used with infants, measuring generic functional status in 0-15 year old children. The questionnaire asks parents first about the frequency with which their child performed a specific activity (e.g. eats well, sleeps well, turns to sound) or displayed a behaviour (e.g. irritable, moody) in the past 2 weeks. Any items to which the parent responded that their child performs poorly are then probed further to ascertain whether any functional impairment is due 'fully', 'partly' or 'not at all' to a health problem.

- The long version (43 items) has age-appropriate sub-scales and produces total and subscales scores.
- There is a short version with 12 items that are common to all ages; it produces a total score only.

However, this tool has several limitations. Its questions are functionally oriented, with few questions about interactions with others. While the tool has demonstrated validity and reliability, there is limited evidence of responsiveness and successful application in impact evaluations. It has been correlated with different markers of disease severity for children with HIV²¹¹, and was responsive to change in a clinical trial of melatonin treatment for children with insomnia.²¹² It is available by agreement from the authors at a cost of \$25 (rstein@aecom.yu.edu).

The **Infant and Toddler Quality of Life questionnaire (ITQOL)**²¹³ would be a good alternative to the FS(II) for infants and young children (2 months – 5 years), especially as it measures impact on the family as well as the child. However, it is long (103 items), and has not been validated in infant populations.

- 3) **KINDL (Revised version**²¹⁴⁻²¹⁵, <http://kindl.org/cms/>) is recommended as a potential alternative to the PedsQL for measurement of HRQOL:
- It is relatively short (24 items), asking about how children have been in general or the frequency with which they felt or did things in the past week.
 - It produces both a total score and 6 subscale scores covering key dimensions of health (Physical Wellbeing, Emotional Wellbeing, Self-Esteem, Family, Friends, Everyday Functioning including school).
 - It can be applied to a children with a wide age range (4-16 yrs)

However, there is as yet little evidence of the responsiveness of the KINDL and there are almost no versions for LMICs.

While the PedsQL is a tool for all-round application, there are a number of other tools with good psychometric properties and comprehensive content which produce profiles (subscales, without total scores) of impact that could be useful in describing impact more comprehensively than the PedsQL. These are:

- 4) **The Child Health Questionnaire**²¹⁶ is a family of generic questionnaires originating in the USA and measuring physical and psychosocial wellbeing among 5-18 year old children.
- The scale produces 2 summary scores (Physical and Psychosocial health) as well as 14 subscales that include concepts not produced by the generic PedsQL such as self-esteem and bodily pain.
 - Four of the 11 subscales measure the impact on the family –in terms of time, emotions, family activities and cohesion.
 - The questions on time impact (*Were you limited in the amount of time you had for your own needs because of your child's - physical health; emotional wellbeing or behaviour?*) might be useful in validating measures of household productivity/poverty.
 - There are both parent-report versions of long (50 items) and short (28 item) lengths, as well as a self-report version for children 10-18 years (which is quite long - 87 items).
 - It is widely used and has been cross-culturally adapted to >32 countries including 8 LMICs
 - Licenses for using the CHQ can be purchased from HealthAct (<http://www.healthact.com/>)

5) **DISABKIDS** ²¹⁷⁻²²⁰

The DISABKIDS tools have been developed across 7 European countries specifically in order to assess the impact of disabilities and chronic health conditions on HRQOL of children aged 8-16 years.

- The long version shows (37 items) shows good psychometric properties and a short version is now available (although psychometric properties not demonstrated)
- The tools produce a profile of 6 subscales conceptualised around health and disability: Independence, Physical Limitation, Emotion, Social Inclusion (e.g. acceptance), Social Exclusion (e.g. stigma, being left out), and Treatment.
- It has add-on modules of 10-12 items for specific diseases including epilepsy and cerebral palsy²²¹
- There is also a version available for 4-7 year olds (DISABKIDS Smiley) which produces a total score only.
- The wording of the questions "*emphasises the impact of a certain chronic health condition and is not applicable for healthy children*". This means that it might not be applicable to a control group of able-bodied children; however it may be more sensitive in detecting changes in HRQOL as a result of its narrower specificity.
- A disadvantage is that there have been no cross-cultural adaptations to LMICS. User agreements need to be sought from the developers and may require payment (<http://www.disabkids.de/>)

6) **KIDSCREEN** ²²²⁻²²³

The KIDSCREEN tools have been developed in parallel with DISABKIDS across several European countries. It also assesses HRQOL in children aged 8-18 yrs but is generic to children with and without disabilities.

- It is available in different lengths (52, 27 items) producing 10 or 5 subscales covering Physical/Psychological Wellbeing, Autonomy, Parent Relations, Social Support and Peers, School, Social acceptance (including bullying), and financial resources.
- A disadvantage is that there have been no cross-cultural adaptations to LMICS. User agreements need to be sought from the developers and may require payment (<http://www.kidscreen.de/>)

Table 4.6. Tools measuring Quality of Life, Health Status and related concepts in Children

| Acronym Σ | Concept | Purpose | Items | Rater | Subscales | Total/ sub-scale scores | Target popln (years) | Country of origin (Language) | Country adaptatio ns (LMICs) | Content | Validit y | Reliabilit y | Citations per year |
|---------------------------|-------------------------------------|--|----------------|-------------------------|---|-------------------------------|------------------------------------|------------------------------------|------------------------------------|---------------------|--------------|-----------------|-----------------------|
| WCHMP ²²⁴⁻²²⁵ | Health and morbidity | Research and health service planning | 16 | Parent | 10: General Health Status; Acute minor illness status; Behavioural Status; Accident status; Hospital Admission Status; Immunization Status; Acute Significant Illness Status; Chronic Illness Status; Functional Health Status; HRQOL | N/Y | Generic (0-5) | UK (English) | - | (+) | (+) | (-) | 1.9 (1996) |
| FS II(I R) ²¹⁰ | Functional Status/ Health Status | Evaluate alternative ways of delivering health care | 43 or 12 | Parent | 2: General Health Status and an age specific scale: Responsiveness (0-2 yrs), Activity (2-3 yrs), Interpersonal Functioning (≥4 yrs) | Y/Y | Generic (0-16) | USA (English, Spanish) | - | (++) | (++) | (+) | 9.2 (1990) |
| ITQOL ²¹³ | HRQOL | | 103 | Parent | 7 Infant Scales: Physical Abilities; Growth & Development; Bodily Pail/Discomfort; Temperament & Moods; General Behaviour; Getting along with Others; General Health Perceptions. 3 Family impact scales: Impact - Emotional; Impact-Time; Impact - Mental Health. | N/Y | Generic (2 months – 5yrs) ◊ | Canada (English) | - | (+) | (++) | (++) | 3.1 (2003) |
| RAND HSMC ²²⁶ | Health Status | Testing hypotheses about health care financing & health status | 159 (un-clear) | Parent | Mental Health; General Health; Social Relations; Satisfaction with Development | | Generic (0-13) | USA (English) | - | (++) | (+) | (-) | 4.1 (1979) |
| TAPQOL ²²⁷ | HRQOL | Outcome measure in medical care | 43 | Parent | 12: Sleeping; Appetite; Lungs; Stomach; Skin; Motor Functioning; Social Functioning; Problem Behaviour; Communication; Anxiety; Positive Mood; Liveliness. | | Generic (1-5) | Netherlands (Dutch) | China (Mandarin) | (++) | (++) | (-) | 5.7 (2000) |
| HSPS-PS ²²⁸ | Health Status | Assess health status across populations and longitudinally | NR | Parent Clinician | 12: Vision ,Hearing , Speech; Mobility; Dexterity; Self-care; Emotion; Learn/remember; Think/problem-solve; Pain; General health; Behaviour | N/Y | Generic (2.5 - 5) | Canada, Australia (English) | - | (++) | (+) | (-) | 2.8 (2005) |
| CHSCS-PC ²²⁹ | Health Status | Inform decisions about | 12 | Parent Nurse | 10 subscales: Vision, Hearing, Speech, Mobility, Dexterity, Self-care, Emotion, Learning and | Y/Y | Generic (2-5) | Canada (English) | - | (+) Based on HUI | (0) | (0) | 0.3 (2006) |

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| | | therapeutic alternatives | | | Remembering, Thinking and Problem Solving, Pain. | | | | | | | | |
| PedsQL 4.0 Generic Core ^{16, 230} | HRQOL | Clinical trials, research, clinical practice, school health settings, and community populations | 23 | Self (5-18) Parent (2-18) | 2 summary scores: Physical Health; Psychosocial Health 4 subscales: Physical functioning, Emotional functioning, Social functioning, School functioning | Y/Y (Total/ Summary/ Subscale | Generic (2-18) (Also 18-25 ²³¹) | USA (English, Spanish) | Argentina, Brazil, Chile, China, India, Indonesia, Iran, Mexico, Pakistan, Palestine, Peru, Philippines, S.Africa, Singapore, Taiwan, Uruguay, | (++++) | (++) | (+) | 53.3 (2001) |
| Nordic QOLQ for Children ²³²⁻²³³ | QOL | NR | 74 | Self with parent | 4: Global sphere (environment); External Sphere (socio-economic status of household); Interpersonal Sphere (social networks); Personal Sphere (psychological wellbeing) | Y/Y | Generic (2-18) | Sweden (Swedish) | - | (+) | (0) | (0) | 1.9 (1993) |
| DISABKIDS Smiley ^{217-218, 220, 234} | HRQOL | Assess impact of chronic health condition/ disabilities | NR § | Self € Parent | | Y/N | CWDs (4-7) | Austria, France, Germany, Greece, the Netherlands, Scotland, Sweden | - | (++++) | (+) | (-) Child (+) Parent | n/a (2008) |
| HUI Mark II ^{146-147, 181} | HRQOL/ Health Status | Describe health status, Population health surveys, clinical studies, CUAs | 7 | Self (≥ 8 yrs) Parent (≥ 5 yrs) | Sensation, Mobility, Emotion, Cognition, Self-care, Pain, Fertility | Y/Y | Generic (≥ 5yrs) | Canada (French, English) | Argentina, China, Brazil, China, Cuba, Korea, Mexico, S. Africa, Singapore, Thailand, Honduras, Colombia, Uruguay | (+) | (+) | (+) | 19 (1995) |
| C-QOL ²⁰⁰ | QOL | NR | 54 | Self Carer | 26 facets covering the following domains: physical, psychological, levels of independence, social relationships, environment, | Y/Y | Generic (5-8) | Thailand | - | (++) | (+) | (+) | 0.8 (2000) |

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| | | | | | spirituality, religion & personal beliefs, Rights | | | | | | | | |
| TedQL ²³⁵⁻²³⁶ | QOL | Patient involvement in treatment decisions; measure long-term outcomes of treatment | 30 | Self | 3: Ability (climbing, running, writing, and drawing); Social (family/ friends); Mood (feelings/mood) | Y/Y | Generic (5-9) | UK (English) | - | (+) | (-) | (+) Total (-) Sub-scale | 1.4 (2001) |
| KINDL (R) ²¹⁴⁻²¹⁵ | HRQOL | Epidemiological, clinical and evaluative studies | 24 π | Self Parent | 6: Physical Wellbeing; Emotional Wellbeing, Self-esteem, Family, Friends, Everyday Functioning (school or nursery) | Y/Y π | Generic (4-16) | Germany (German) | Singapore (English) | (+) | (++) | (+) Total (-) Subscales | 13.2 (1998) |
| CHRIS ²³⁷⁻²³⁸ | HRQOL | Enhance children's understanding of and participation in their own disease management | 20 § | Self Parent | 4 subscales: Physical Functioning, Emotional Functioning, Role Functioning, Energy | N/Y | Chronic Illness (5 – 18) | USA (English) | - | (0) | (+) | (+) | 6.8 (1998) |
| CHRS ²³⁹ | Health Status | Studies based on group comparisons, multivariate analyses | 17 | Self | | Y/N | Generic (9-12) | USA (English) | - | (+) | (++) | (+) | 0.35 (1990) |
| CHQ ²¹⁶ CHQ-CF87 ²⁴⁰ CHQ-PF50 ²⁴¹ CHQ-PF28 ²⁴² | Physical and psychosocial health status and wellbeing | | 87 50 28 | Self (10-18) Parent (5-18) | 2 summary scores: Physical and Psychosocial health). 14 sub-scales: Physical Functioning, Role Functioning Emotional/ Behaviour; Role Functioning Physical; Bodily Pain; General Behaviour; Mental Health; Self Esteem; General Health Perceptions; Parental Impact Emotional; Parental Time Impact; Family Activities; Family Cohesion; Change in Health | N/Y | Generic (5-18) ‡ | USA (English) | >32 ²⁴³ countries including Argentina, Brazil, Chile, China, Korea, Mexico, Sudan, Taiwan | ‡ | (++) | (+) (+) (-) | 10.8 (1998) |
| CLQI ²⁴⁴ | HRQOL | Provide information on health impact of different | 12 | Parent | Content: Energy, Difficult Behaviour, Pain, Sleep, Appetite/Diet, Games/Play, Friends/Family, Teasing, Missing School, School Progress, Hospital | Y/N | Generic (5-16) | UK (English) | - | (0) | (+) | (0) | 9 (2006) |

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| | | diseases | | | Visits, Treatment at Home | | | | | | | | |
| CHIP-CE 245-247 | Health status | Describing health, monitoring outcomes of policies & services | 45 § 76 | Self Parent | 5 domains: Satisfaction, Comfort, Resilience, Risk Avoidance, Achievement + 12 sub-domains | N/Y (domain and sub-domains) | Generic (6-11) | USA (English) | - | (+) | (+++) | (-) Child-report (++) Parent-report | 6.3 (2004) |
| EXQOL (computer-delivered) 248-249 | HRQL | | 12 § | Self € | Content includes: confide in others; sleep; afraid of hurting self; stomach aches & headache; popular in class; diet; schoolwork; appearance; fit; tired; exclusion; making friends; choice in activities | Y/N | Generic (6-11) | UK (English) | - | (++) | (+) | (-) | 1.1 (2000) |
| TACQOL ²⁵⁰⁻²⁵¹ | HRQOL | Evaluating health /health care, treatment of individual patients | 56 | Self (8-15) Parent (6-15) | 7: Physical Complaints; Motor; Autonomous; Cognitive; Social; Positive Moods; Negative Moods. | N/Y | Generic (6-15) | Netherlands (Dutch) | - | (++) | (+) | (+) | 9.3 (1998) |
| GCC ²⁵²⁻²⁵³ | QOL | | 25 | Self | None. Content: General effect, peer relationships, attainments, relationships with parents, general life satisfaction) | Y/N | Generic (6-16) | UK (English) | - | (+) | (+) | (+) | 2.3 (2000) |
| PQ-LES-Q ²⁵⁴ | QOL | Evaluation of therapeutic outcomes, service evaluation | 15 | Self | Content: Health, Mood/feelings, School/learning; Helping at home; getting along with friends/family; free time/play; getting things done; love/affection; getting/buying things; energy; feelings about yourself; life overall | Y/N | Generic (6-17) | USA (English) | - | (+) | (+) | (++) | 1.8 (2006) |
| HAY? ²⁵⁵⁻²⁵⁶ | QOL | Evaluate the effectiveness of interventions | 29 | Self Parent | 4: Physical Activities; Cognitive Activities; Social Activities, Physical complaints | N/Y | Generic (8-12) | Holland (Dutch) | - | (++) | (+) | (-) | 2.7 (2000) |
| QLQC ²⁵⁷ | HRQOL | NR | 118 | Self Parent | Physical, Psychological and Social Functioning | N/Y | Generic (8-12) | Netherlands (Dutch) | - | (++) | (+) | (-) | 0.4 (1999) |
| CQOL ²⁵⁸ | HRQOL | | NR | Self Parent | 15: Activities, Appearance, Communication, Continence, Depression, Discomfort, Eating, Family, Friends, Mobility, School, Sight, Self-care, Sleep, Worry. | Y/Y | Generic (9-15) | UK (English) | - | (+) | (+) | (-) | 2.5 (1997) |
| 17D ²⁵⁹ | HRQOL | Self-assessment of HRQOL in pre- | 17 § | Self | Content: Mobility, breathing, School and Hobbies, Friends, Hearing, Vision, Eating, Elimination, Vitality, Sleeping, Anxiety, | Y/N ϕ | Generic (8-11) | Finland (Finnish) | - | (++) | (+) | (+) β | 2.6 (2006) |

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| | | adolescents | | | Discomfort and Symptoms, Learning and Memory, Ability to Concentrate, Depression, Speech, Physical appearance | | | | | | | | |
| DISABKIDS Chronic Generic Module 217-220 | HRQOL | assess impact of chronic health condition/ disabilities | 37 | Self 8-16 | 6: Independence, Physical Limitation, Emotion, Social Inclusion, Social Exclusion and Treatment | N/Y | CWDs (8 – 16) See above for version for 4-7 yrs | Austria, France, Germany, Greece, Sweden, Netherlands, UK. | - | (++++) | (++) | (+) | 5 (2005) |
| EQ-5D-Y ^{164, 260} | HRQOL | Population surveys, routine monitoring, clinical research & practice | 5 | Self | 5: Mobility, Self-care, Usual activities, Pain/Discomfort and Anxiety/Depression | N/Y | Generic (8-18) | Germany, Italy, South Africa, Spain, Sweden, Netherlands, UK | - | (++) | (+) | (-) | n/a 2010 |
| KIDSCREEN-52 ²²³ | HRQOL | Representative national & European health surveys to monitor, evaluate & plan health prevention | 52 | Self Parent | 10: Physical Wellbeing; Psychological Wellbeing; Moods & Emotions; Self-perception; Autonomy; Parent relations/home life; Social Support & Peers; School environment; Social acceptance/bullying; Financial resources | N/Y | Generic (8-18) | ≥7 European Countries (Austria, Germany, UK, France, the Netherlands, Spain, Switzerland) | Argentina, Korea | (++++) | (++) | (+) | 12.6 (2005) |
| KIDSCREEN-27 ^{222, 261} | HRQOL | Epidemiological & Clinical studies | 27 | Self Parent | 5: Physical Wellbeing; Psychological Wellbeing; Autonomy & Parent Relations; Peers & Social Support; School Environment | N/Y | Generic (8-18) | 13 European Countries | Brazil, Chile, Korea | (++++) | (+++) | (-) | n/a (2007) |
| KIDSCREEN-10 ²⁶² | Mental Health and Wellbeing | Screen for deficits in mental health and wellbeing | 10 | Self Parent | None. Content: Fit and well; Full of energy; felt sad; felt Lonely; had enough time for yourself; been able to do the things that you want to do in your free time; parent(s) treated you fairly; had fun with your friends; got on well at school; been able to pay attention | Y/N | Generic (8-18) | 13 European Countries | - | ? | (+) | (+) | n/a (2009) |
| PIE ²⁶³⁻²⁶⁴ | Child's perception of illness experience (one aspect of QOL) | Evaluate impact of treatment/ outcome of intervention | | Self Parent | 10: Physical appearance; Interference with Activity; Disclosure; School work; Peer Rejection; Parental Behaviour; Manipulation; Preoccupation with Illness; Food; Treatment. | Y/Y | Chronic illness (8-24) | UK (English) | - | (+) | (+) | (+) Total (-) Subscales | 3 (1995) |

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|----------------------------|--------------------------|--|-------------------|------|---|------------------------------|-----------------|-------------------|-----------|--------|------|-------------------------------|-------------|
| 16D ²⁶⁵ | HRQOL | Self-assessment of HRQOL in adolescents | 16 | Self | Content: Mobility, Breathing, School and Hobbies, Friends, Hearing, Vision, Eating, Elimination, Vitality, Sleeping, Anxiety, Discomfort and Symptoms, Mental Function, Depression, Speech, Physical Appearance | Y/N ^o | Generic (12-15) | Finland (Finnish) | - | (++) | (+) | (+) β | 3.8 (2006) |
| CHIP-AE ²⁶⁶⁻²⁶⁷ | Health status | Epidemiologic surveys, assess impact of health services & policies | ≥ 107 | Self | 6 domains: Discomfort, Satisfaction with Health, Disorders, Achievement, Risks, Resilience + 20 sub-domains | N/Y (domain and sub-domains) | Generic (11-17) | USA (English) | - | (++++) | (++) | (++) | 7.4 (1995) |
| COOP ²⁶⁸ | Health & Social Problems | Detection & management of adolescent health & social problems; measure impact of interventions | 6 (Picture Cards) | Self | 6: Physical Fitness, Emotional Feelings, School Work, Social Support, Family Communications, Health Habits) | N/Y | Generic (12-21) | USA (English) | - | (+++) | (+) | (0/+) Use correlation only | 2.25 (1994) |
| DHP-A ²⁶⁹ | HRQOL | Assessment of health status in adolescents | 17 | Self | 10: Physical, Mental, Social, General Health, Perceived Health, Self esteem, Anxiety, Depression, Pain; Disability | N/Y | Generic (12-18) | France (French) | Vietnam | (+) | (+) | (-) | 0.4 (2005) |
| QOLPAV ²⁷⁰ | QOL | Assess current state of coping & functioning, service needs, illness & treatment effects | 54 | Self | 3: Being (Physical, Psychological, Spiritual); Belonging (Physical; Social; Community); Becoming (Practical Leisure; Growth) | Y/Y | Generic (14-20) | Canada | - | (++) | (+) | (+) | 5.1 (1996) |
| QOLQA ²⁷¹ | QOL | Compare adolescent QOL internationally | 70 | Self | 5: Physical, Psychological, Independence, Social Relationship; Environment (e.g. security) | Y/Y | Generic (12-15) | Japan, China | Singapore | (++) | (0) | (+) | 0.9 (2000) |
| TQOLQA ²⁷² | QOL | Not stated | 38 | Self | 7: Family, residential environment, personal competence, social relationships, physical appearance, psychological wellbeing, and pain | Y/Y | Generic (13-15) | Taiwan | - | (+++) | (+) | (+) | 0.4 (2005) |
| VSP-A ²⁷³ | HRQOL | Discriminative, predictive, evaluative instrument | 40 | Self | 6: Psychological Wellbeing; Energy; Friends; Parents; Leisure; School | Y/Y | Generic (11-17) | France (French) | - | (++) | (++) | (+) Total (-) | 4.2 (2000) |

| | | | | | | | | | | | | Subscales | |
|------------------------|-------|---|----|------|---|-----|-----------------|-----------------|-----------------------------|--------|------|-----------|------------|
| VSP-A12 ²⁷⁴ | HRQOL | Discriminative, predictive, evaluative instrument | 12 | Self | None. Content includes Psychological Wellbeing; Energy; Friends; Parents; Leisure; School | Y/N | Generic (11-17) | France (French) | - | (++) | (++) | (++) | 0.7 (2004) |
| YQOL-R ²⁷⁵ | QOL | Assess the outcomes of interventions | 41 | Self | 4: Self; Relationship; Environment (e.g. neighbourhood, future, safety); General QOL | Y/Y | Generic (12-18) | USA (English) | Mexico, Brazil, Puerto-Rico | (++++) | (++) | (++) | 4.0 (2002) |

ACS = Activity Card Sort; **CHIP-CE** = Child Health and Illness Profile - Child Edition; **CHIP-AE** = Child Health and Illness Profile - Adolescent Edition; **CHRIS** = Child Health Ratings Inventory; **CHRS** = Children's Health Rating Scale; **CHQ** = Child Health Questionnaire; **CQOL** = Child Quality of Life Questionnaire; **C-QOL** = Quality of Life Measure for Children; **CHSCS-PC** = Comprehensive Health Status Classification System for Pre-school Children; **COOP** = Dartmouth COOP Functional Health Assessment Charts for Adolescents; **DHP-A** = DUKE Health Profile-Adolescent version; **Exqol** = Exeter QoL scale; **FS II(R)** = Functional Status II (Revised); **GCQ** = Generic Children's Quality-of-life measure; **HAY?** = How are You? (Generic Part; there is an asthma-specific part too); **HSPS-PS** = Health Status Classification System of Pre-School Children; **HUI** = Health Utilities Index; **NR** = Not Reported; **TACQOL** = TNO AZL Child Quality of Life Questionnaire; **PEDI** = Pediatric Evaluation of Disability Inventory; **PedsQL** = Pediatric Quality-of-life Inventory; **PIE** = Perceived Illness Experience; **PQ-LES-Q** = Pediatric Quality of Life Enjoyment and Satisfaction Questionnaire; **QLQC** = Quality of Life Questionnaire for Children; **QOLPAV** = Quality of Life Profile: Adolescent Version; **QOLQA** = Quality of life Questionnaire for Adolescents; **RAND HSMC** = Rand Health Status Measure for Children; **TACQOL** = TNO-AZL Child Quality of Life; **TAPQOL** = TNO-AZL Preschool Children Quality of Life; **TQOLQA** = Taiwanese QOL questionnaire for Adolescents; **VSP-A** = Vecú et Sante Perçue de l'Adolescent; **WCHMP** = Warwick Child Health and Morbidity Profile;

ð **HUI Mark II** originally developed for paediatric cancer patients. Although the authors say that it is generic, it still reflects, in content and wording, application for the original population.

β Did not use preferred test of reliability but another one for test-retest (Bland Altman^{259, 265})

§ Items and/or response options are illustrated with pictures (17D, CHIP-AE Child-report, CHRIS version 5-12 yr old children, DISABKIDS Smiley for 4-7 yrs)

⊕ Subscales are only 1 item each and are therefore not considered a scale

€ Child respondents of the DISABKIDS/EXQOL can complete the questionnaire with the assistance of the interviewer

‡ The development of the content of the CHQ could not be reviewed because it is published in the User Manual which was inaccessible. A pre-school version under development²⁴²

◇ **ITQOL** psychometric validation conducted in population of children 3-4 years old.

∑ Tools whose names are underlined produce single summary scores that are preference values/weights that can be used to calculate QALYs for CEAs. The **EQ-5D-Y** is a new tool that does not yet have preference values attached to the different health status classifications.

¶ **KINDL** - The self-reported version of the KINDL for 4-7 years olds (Kiddy-KINDL) has 12 items only (2 from each of the 6 domains) and produces a total score only.

4.6. Tools measuring Utility Values in Adults and Children

Tools eliciting Utilities Values for adults and children with disabilities have been underlined in Tables 4.4. and 4.6, respectively. These tools are:

- EQ-5D (adults)
- SF-6D (adults)
- QWB (adults)
- HUI Mark II/III (children/adults)
- 16D (children)
- 17D (children)

The utility values elicited by these tools represent populations preferences for different health states, and have been derived from high-income populations in North America. They are not really appropriate to use in LMICS, and have been criticised conceptually (see 1.4.7). Their content is often more limited than non-preference-based measures, and subscales are based on single items.

The limitations of using these measures in CUA must be kept in mind when undertaking impact evaluations in LMICs. Non-preference based measures of outcomes (e.g. WHODAS 2.0 total score) can be applied in cost-effectiveness analyses instead.

5. REVIEW OF POVERTY MEASUREMENT

Poverty is a multidimensional phenomenon. Poverty is traditionally evaluated using a monetary measure, but other dimensions can be included such as health, education, shelter, and social involvement. In this review we identify tools that measure the multidimensional aspects of poverty and we define poverty as an inadequate fulfilment of basic needs, including food, clothing, shelter, health, education, and social involvement.

Poverty should typically be measured at the household level rather than at the individual level, as in most LMICs the financial resources are shared within a household. This means that the level of measurement for poverty is not the same as for the other components of impact such as Participation or Quality of Life. Poverty can also be measured at the community level, for instance through assessing the proportion of households below the poverty line, but these techniques are not discussed in this review as the unit of interest is PWDs and their families.

We have structured this section differently to the previous sections. This is because household poverty is most often objectively assessed from locally-specific information about income, expenditure, and household assets that are identified during pilot work in the local setting. Thus standardized questionnaires are usually not available. However, since poverty is a crucial area in which impact may occur we still wanted to provide a description in this review of tools available. We will therefore describe different techniques available for measuring poverty, rather than focusing on specific tools or questionnaires. We will include examples of these techniques (Table 5.1) so that they can be adapted to particular settings.

5.1. Income

A basic measure of poverty is lack of income. Technically income is defined as consumption plus change in net worth, but usually it is calculated in terms of wages earned. A person is considered to be poor if his/her income is below a specific threshold. Poverty can therefore be assessed by measuring the income of the individual or the household head, or else the sum of wages earned by household members. The advantage of the use of income for assessing poverty is that it is relatively quick and simple to collect the data.

However, there are also a number of limitations:

- People may be reluctant to disclose the full extent of their income to interviewers, particularly if it is obtained illegally. They may fear that they will be charged for services, or that they will be reported to the tax offices.

- A lot of food and goods that are used (consumption) in LMICs is obtained through bartering, home production (e.g. on their own farms) and informal markets. This means that people may have little income, and therefore income may not be a meaningful concept to use to assess level of poverty.
- Income may vary a great deal from month to month for many people in LMICs, for instance if they are dependent on seasonal earnings. This means that measuring income at one point in time may not give an accurate reflection of the level of poverty of the household.

For these reasons, income may be useful as a measure of poverty in high income settings but is not considered a reliable measure of poverty in LMICs.

5.2. Consumption expenditure

An alternative measure to income is consumption expenditure. This is the sum of the value of all goods purchased and those that are provided from own production, or from payment in kind or as gifts for the household. Questionnaires usually ask about consumption of 80-100 items. The list of items should be adapted so that it is locally relevant, and for this reason standard tools are not available. In addition, the estimated monthly rental value of the house (for home owners) and of durable goods is included. The total is added for the household and divided by the number of household members to calculate per capita household consumption (usually monthly).¹

Case study: As one example, consumption expenditure was measured as part of the Cataract Impact Study in Kenya, the Philippines and Bangladesh.²⁷⁶ The person in the household responsible for finances was interviewed about household consumption. He/she was asked to recall the monetary value of food and other items that was purchased, consumed from home production, received as payment in kind or as gifts. In total 80-90 items were included per country, and the specific items were varied so that they were relevant to each country.

Items were included on food (42-52 items per country), education (3 items), health (5 items), expenses on the household (9 items), and personal expenses (21-22 items). In total, 85 items were included in the questionnaire in Kenya, 90 in the Philippines and 79 in Bangladesh. The informant was asked to recall the monetary value of food that was purchased, consumed from home production, received as payment in kind or as gifts. Consumption expenditure was assessed over a one

¹ There are other options to calculating expenditure per capita, for instance using weighting scales so that children less heavily than adults, or that economies of scales are included for larger households⁶⁵

month period. This was then divided by the number of household members to assess the monthly per capita expenditure.

Per capita expenditure can be used to rank people in a community on a poverty scale or to compare differences between two groups (e.g. people with disability compared to people without disability). Alternatively, a poverty line can be established, which is a threshold below which a person is defined as “poor” (e.g. less than \$1 per day). The proportion of the community below the threshold can then be estimated. It may be of interest to estimate poverty through the total expenditure on food consumption as a fraction of total expenditure.

The Living Standards Measurement Survey has produced an extensive sample questionnaire to measure consumption.²⁷⁷ This is best considered as a template that needs to be adapted to be locally relevant, rather than as an off-the-shelf survey.

Consumption expenditure is generally preferred over income as a means of measuring poverty, and its use is recommended by the World Bank. This is because current consumption tends to fluctuate less than income, and so is a better measure of long-term average wellbeing. In addition, data on consumption are more accurately collected than income data, both because respondents in the informal sector may have difficulty recalling all the types of income they receive, and people may not report their income accurately because of taxation and other concerns.²⁷⁸

There are also limitations of this method. The list of items recorded needs to be setting-specific and so pilot work is required to adapt the questionnaire. Consumption expenditure is estimated more accurately the greater the number of items on the list (80-100 is typical), and so collection of data is relatively time consuming (at least 15 minutes). Shortened expenditure forms can be used, but they are less reliable. There is also a large analytical burden, requiring input from someone with statistical expertise.

5.3. Assets

Asset ownership can serve as a proxy to monetary poverty that is ideally captured by income or consumption. Typically, a household is asked about the ownership of items that are locally relevant measures of wealth. These may include electrical appliances (e.g. radio, TV), animal ownership (e.g. chickens, cows) as well as questions about the quality of the household (e.g. material of roof and walls). In total approximately 10-20 questions are usually included, and these items must be locally relevant. These answers are then used to assign a “wealth” score for each household either through simple counts of the number of assets owned or by

assigning a weight to each asset. The weights are either determined through local consultation or by using Principal Components Analysis, which is a statistical technique for producing a score based on a list of items.²⁷⁹ Other weighting systems are used more rarely (e.g. proportional possession weighting). Household quality alone can also be used as a measure of poverty.

These questionnaires can be derived locally, asking people about locally appropriate measures of wealth. Alternatively, in some countries standard tools are available. One example is in India where the Standard of Living Index was created during the National Family Health Survey.²⁸⁰ It is composed of 27 items, including consumer durables, agricultural machinery, housing conditions and access to basic services. Each component has a respective weight. The possession of assets by the household together with the weights is used to create a score for each household.

The advantage of the use of asset scores for assessing poverty is that these data are relatively quick to collect, and to analyse (although statistical input is needed for undertaking Principal Components Analysis). Asset scores provide a measure of long-term wealth.

One of the disadvantages of this method is that the scales often have to be locally derived, although this is generally not time-consuming. Asset scores are not always closely related to consumption expenditure: a review of 36 datasets showed weak agreement for 22 studies, moderate agreement for 10 and strong agreement for only 4 studies.²⁸¹ In addition, since asset scores provide a long-term measure of poverty they are usually not sensitive to change, as it takes time to accumulate wealth in terms of assets. Asset scores may therefore fail to detect an impact of interventions on poverty within the time scale of an impact assessment study.

5.4. Self-rated wealth

Self assessments of poverty or wealth provide useful summary measures of poverty. Standard questions do not exist, but may be locally devised. Examples include "Do you have enough" or "Do you consider your income very low, rather low, sufficient, rather high or high". In one study participants were asked the question "On a scale of 1 to 10, how well-off do you think your household is in relation to the other households in the village?". This score was closely related to more detailed measures of consumption expenditure and assets.²⁷⁶

The advantage of this measure is that it is rapid to collect and analyse. The limitation is that self-perceptions of wealth may take time to change, and so these measures may not be useful to assess impact of an intervention.

5.5. Observer or peer assessments

Poverty can also be measured through observer assessments. For instance, people within a community can be considered “poor” if they are eligible for subsidies on account of poverty (e.g. rations or food stamps or access to social welfare grants). This method can provide a rapid measure of poverty. However, subsidy systems are not perfect and so may not provide an accurate estimate of poverty.

Peer assessments or participatory assessments can also provide measures of poverty. Participatory Wealth Ranking is one example.²⁸² For this method, residents draw up a list of the households in their community (usually 50-200). Smaller meetings are then held with 4-6 residents. Residents are asked to characterise households that are “very poor”, “poor, but a bit better off” and those that are “doing OK” (“general statements”). The residents then rank the households from the poorest to the wealthiest according to the definitions provided. The ranking process can be repeated with different groups of 4-6 community members, so that each household is ranked several times. A household wealth index for each household can then be calculated as the rank assigned or the average of multiple ranks. A cut-off can then be applied to the household wealth index to group households into wealth bands on the basis of these local perceptions of poverty.

The advantage of participatory processes is that they provide detailed insights into local poverty issues and they are often more rapid to undertake than consumption expenditure surveys. However, they are limited as they may only be appropriate in small geographical areas and may be difficult to generalise. They are generally not used for impact assessments.

5.6. Nutritional poverty

Nutritional poverty can be used as a measure of overall poverty. There are several advantages to this method. Food is a basic human need and therefore lack of access to food can provide a measure of extreme poverty. Furthermore, nutrition is a key element of poverty since adequate nutrition is a prerequisite for an acceptable level of wellbeing. The tools described below are generally relatively quick and easy to use (except food frequency questionnaires and diet diaries). However, nutrition is only one element of nutrition and lack of food as a measure of poverty may only be relevant in situations of relatively extreme poverty and this weakness applies to all measures of nutritional poverty.

Nutritional poverty can be measured in a number of ways, including the following:

- a) **Food security:** Food insecurity is defined as "*whenever the availability of nutritionally adequate and safe foods or the ability to acquire acceptable foods in socially-acceptable ways is limited or uncertain*". This is often assessed through locally relevant questions on food availability and reliability. A few standard scales exist, such as the Core Food Security Module which asks 18 questions, including items on whether the family can afford food, or whether skipping meals is habitual. This is used to characterize the households as "Food secure", "Food insecure", "Moderate hunger" or "Severe hunger".
- b) **Calories consumed:** Caloric intake can be estimated through standardised techniques, such as through the use of food-frequency questionnaires or consumption diary. Typically, the amount and frequency of consumption of different items is recorded and this is translated into caloric intake using standard nutrition tables. These questionnaires and nutrition tables are available for most settings. People can then be categorised as receiving sufficient calories, or not, or compared in terms of mean calories consumed.
- c) **Malnutrition:** Malnutrition can be measured through anthropometric measurements on children. The height, weight and age of children must be recorded. Children who are short for age according to standard scales are then classified as "stunted", which is a measure of long-term food insufficiency. Children who are thin for height are classified as "wasted", which is a shorter-term measure of food insufficiency.

5.7. Other non-monetary measures of poverty

Other measures of poverty focus on non-monetary domains. These include: level of education achieved, literacy, occupational status, participation in employment and participation in school. These questions can be used individually to assess level of poverty. Alternatively, composite scores can be developed based on a combination of these questions, either adding the questions together or using weighting of the individual questions.

As an example, a study conducted in Pakistan developed a novel household poverty variable by using a combination of occupation and literacy of people living in the house.²⁸³ Household occupation was determined based on the highest status occupation within the household (non-manual, manual or other). A "literate household" was one that contained at least one literate household member. Combining household occupation and household literacy gave three categories for

household poverty: non-manual and literate ("affluent households") > non-manual and illiterate plus manual and literate ("medium households") > manual and illiterate ("poor households").

The advantage of these scores is that they are simple to collect and analyse, and can assess dimensions of poverty beyond monetary. However, they may produce relatively crude measures of poverty and so may not be sufficiently sensitive to measure the impact of an intervention.

5.8. Summary with Recommendations for CBM Impact Evaluations

In summary, assessment of consumption expenditure remains the gold standard method for assessing poverty in LMICs and for impact assessment. Income may provide a useful measure in high income countries. These measures are therefore recommended for measuring change in poverty during an impact assessment.

Other measures of poverty, including assets, self-rated wealth, participatory appraisal or self-rated wealth are more rapid to collect, but measure a more limited aspect of poverty and may be less sensitive to change during an impact assessment. They may, however, provide useful measures for comparing people with and without a condition in terms of poverty.

You may wish to include several indicators or measures of poverty so that these can be triangulated.

Table 5.1. Methods for Household Poverty Measurement

| Measure | Concept | Example question | Number of questions | Analysis burden | Strengths/Limitations | Examples of use |
|--------------------------------|--|---|---|---|--|-----------------|
| Financial measures | | | | | | |
| Income | Sum of wages earned by household Or Income of head of household | What is the average monthly income of your household? | 1-2 | Low | + Simple to collect - People may be reluctant to share income data - May not capture work for own production | 284-285 |
| Consumption expenditure | Sum of the monthly value of all goods purchased and those that are provided from own production, or from payment in kind or as gifts for the household | For your household in the last month, what was the value of tomatoes that you: - consumed from home production? - Purchased? - Received as gifts? - Received as payment in kind? | 80-100 typically Shorter versions available, but less reliable | High (sum the cost of all the items and divide by household size to estimate household per capita expenditure) | + Gold standard measure of household poverty - Time consuming to collect and analyse with high researcher burden - Questions must be context specific and pilot tested | 276, 286 |
| Assets | Household score based on ownership of assets | Does the household own any of the following: television, car, radio? What is the material used to construct the walls of the household? How many cattle does the household own? | Typically 10-15 | Moderate (Devise score based on answers to individual items) | + Simple to collect - Questions must be context specific and pilot tested - Long-term measure of wealth and less sensitive to change | 276, 287-291 |
| Self-rated wealth | Self-rated score of household poverty/wealth compared to other households | - On a scale of one to ten how well-off is your household compared to other households in the community? | 1 | Low (analyse single item) | + Simple to collect - Overly simplistic - Long-term measure of wealth and less sensitive to change | 276 |
| Nutritional poverty | | | | | | |
| Food insecurity | Availability of nutritionally adequate and safe foods or the ability to acquire acceptable foods in socially-acceptable ways is limited or uncertain | Are you worried food will run out? Do you skip meals? | Up to 16 | Low (analyse single item or short scale) | + Simple to collect - Focus only on nutritional poverty and so relevant only to poorest settings | 292-293 |
| Calorie consumption | Calories consumed per person per day | - Over the past 12 months how often did you drink tomato juice or vegetable juice? - Over the past 12 months did you eat oatmeal, grits, or other cooked cereal? | >100 | High (Use food frequency questionnaire or food diary with nutrition table to assess calorie intake) | - Time consuming to collect and analyse - Focus only on nutritional poverty and so relevant only to poorest settings | 294 |

| | | | | | | |
|--------------------------------------|---|--|-----|-----|---|------------------|
| Nutritional status | Measure height for age (stunting) and weight for height (wasting) | Anthropometric measures of weight, height and age | 3 | Low | + Simple to collect - Focus only on nutritional poverty and so relevant only to poorest settings | 295 |
| Peer or observer assessment | | | | | | |
| Peer assessment | Measure whether household is judged poor by peers | - Is the household eligible for receiving rations or food stamps? | 1-3 | Low | + Simple to collect - Peer assessments may be unreliable and open to manipulation | 296 |
| Participatory Rural appraisal | - | - | | | | 282 |
| Other measures of poverty | | | | | | |
| Non-monetary measures | Assess occupation, education, literacy, and/or school attendance | What is the highest level of education achieved by the head of household? What is the occupation of the head of household? Does the child attend school? | 1-5 | Low | + Simple to collect + Simple to analyse - May not be sufficiently sensitive to change to allow assessment of impact | 283, 286, 290 |

6. DISCUSSION

6.1. Summary of Recommendations

The purpose of this review has been to produce guidance to CBM on which methods and tools to use when evaluating the impact of their services in the lives of adults and children with disabilities and their families in LMICs in Asia, Africa and Latin America. We have done this through a critical review of the standardised tools that have been developed to measure subjective concepts of impact – such as Activities, Participation, Health Status and Quality-of-life. We have also undertaken a review of methods to measure household poverty.

Below is a summary of conclusions and recommendations:

Measuring Activities and/or Participation in Adults and Children

- There is currently no clear or operational definition on how to distinguish between an Activity and Participation in the ICF.
- We have considered activities to be those that include activities done at the individual level (e.g. self-care), whereas participation to involve activities in society such as employment or education.
- There were 20 generic Activities and/or Participation tools reviewed for adults, whereas only 7 for children.
- We recommend the WHODAS 2.0 for measuring Activities in adults, and the WHODAS 2.0 or Participation Scale for measuring Participation in adults.
- There is little to choose from among childhood A&P tools, as none have been used widely or are available in LMICs. The LIFE-H, CASP and CAPE/PAC could potentially be cross-culturally adapted, however it may be more feasible to use a tool measuring HRQOL for which there is a greater selection of tools that are already used internationally (including LMICs).

Measuring Quality of Life, Health Status and related concepts in Adults and Children

- Concepts of QOL, HRQOL, health status and wellbeing are multidimensional concepts that are often used interchangeably in the literature
- A comprehensive measure of health should include physical, mental and social dimensions.
- We reviewed 17 tools measuring QOL and related concepts in adults and 43 tools for children.
- We recommend using the WHOQOL for measuring broad QOL in adults, and the SF-36 tools for measuring the narrower concept of health status. However, neither of these tools produce a total score which could be used in economic evaluation.

- We recommend using the PedsQL for children aged 2-10 yrs, the FS II(R) in studies involving infants, and/or KINDL(R) if both total and subscale scores are needed.
- If only a description (profile) of impact in the lives of children with disabilities is needed, the CHQ, DISABKIDS or KIDSCREEN tools could be used.
- Use of tools for deriving Utility Values (e.g. EQ-5D, HUI, QWB) for adults and children in LMICS must be undertaken with caution, as weights derived in LMICs are not available.

Measuring Household Poverty

- There are very few standardised 'off-the-shelf' tools for measuring poverty
- Instead, there are several methodological approaches to measuring poverty (e.g. income, expenditure, nutrition, self-rated wealth)
- We recommend that consumption expenditure is measured as the primary estimate of poverty because it provides the most accurate measure of poverty and the measure that is most sensitive to change.
- Consumption expenditure measurement requires adaptation of a standardised data collection tool to local economic settings at the beginning of the evaluation.
- We also recommend that at least one other indicator of poverty is collected in order to cross-check (validate) results. This may include routinely collected background data on (e.g. socioeconomic status), information on asset ownership, specific question(s) on self-reported wealth, or questions/subscales from tools measuring A&P, QOL/HRQOL or Health Status. For example, the Child Health Questionnaire has 4 subscales measuring the impact on the family (see section 4.5)

6.2. Limitations of the Review

There are a number of limitations to the methods used in this review:

- Only self(or parent)-reported generic tools were considered

Many impairment-specific, or condition-specific, tools are available for impact assessment.²⁹⁷⁻³¹¹ These condition-specific tools may be more sensitive than generic tools to detecting small changes that may be important. Furthermore, tools may be developed for a specific impairment but could be applied across impairments (e.g. Screening Activity Limitation and Safety Awareness³¹², Activities Scale for Kids³¹³⁻³¹⁴, Frenchay Activities Index³¹⁵⁻³¹⁶). These tools were not considered in this review, however, as our remit was to identify tools that were developed for use across the range of impairments.

As our focus was on client-centred/perceived outcomes, we also did not consider clinician-rated or observation tools that are often used for rating concepts such as ADL (e.g. Barthel Index³¹⁷⁻³¹⁸, Katz ADL Scale³¹⁹⁻³²⁰) as well as objective

assessments of functional status³²¹ (e.g. Functional Independence Measure³²²) which also provide valuable information about the causal impact of e.g. medical interventions on the poverty, A&P and QOL.

- Tools reviewed based on objective criteria, rather than practical experience

Our recommendations have been made using a set of criteria to guide us toward reliable and valid tools that are widely used and are available in LMICS. It is possible however that tools that look good on paper may not live up to expectations in every situation and study. It is therefore important to pilot test each tool to be used in the setting before starting the study. Furthermore, our subjective opinion may have influenced the recommendations made, especially where many tools were available.

- Access to tools may be restricted

Charges are imposed for the use of some tools (e.g. SF-36, CHQ). Furthermore, although translated versions of the tool may have been developed, these may not be accessible or may need to be further validated.

- Systematic reviews may fail to identify all possible tools

We attempted to be comprehensive in our search strategies, but it is possible that we may have missed some eligible tools. It is unlikely, however, that these were widely used tools.

- No review of indicators

This study has not reviewed tools of indicators as they have limited application as primary outcomes when trying to accurately measure impact for the purposes of statistical analyses and economic evaluations, as opposed to monitoring impact in M&E. It is also difficult to assess critically the performance of different indicators. They can, however be included in data collected in impact evaluations in order to validate primary outcomes. An example of indicators that are being developed is the NGO-IDEAS Impact Toolbox.³²³

- No review of tools to assess the wider impact of rehabilitation

We have not included tools that assessed the wider impact of the intervention, for instance on attitudes in the community,³²⁴⁻³²⁸ or tools developed specifically to measure caregiver of family burden.³²⁹⁻³³⁶ Research studies are always limited by the quantity of data that they can feasibly collect without compromising the quality of results. Poverty was prioritised as the outcome that should be measured at the family level, at the same time as recommending generic tools that can measure

subjective outcomes in non-disabled and disabled family members if resources permit.

6.3. Limitations of the Tools

A number of limitations have also been identified in the tools available for assessing impact.

- Gaps in tools available

There is reasonable availability of tools to assess impact of interventions in adults with disabilities. However, few useful tools are available for assessing activities and participation in children with disabilities in LMICs. Very few paediatric tools have been developed from within LMICS or adapted for LMICs compared to adult tools. Specifically, there is no equivalent of the WHOQOL or WHODAS 2.0 – tools developed simultaneously from low, middle and high income countries – for children. This was reflected also in the lack of child populations and child-centred CCOs represented in the review of impact evaluations of rehabilitation for PWDs in LMICs (Section 3).

- Overlap in concepts within existing tools

The distinctions made between measuring concepts such as Activities, Participation, QOL and Health Status are not always clear. As already discussed, there is significant overlap between Activities and Participation measures within the tools available (e.g. WHODAS). This overlap is consistent with current debates about the definitions and operationalisation of these concepts in the ICF. There is also considerable overlap between A&P and QOL/Health Status concepts – A&P can be considered as dimensions of QOL. For example, the DISABKIDS tool measures HRQOL but includes scales of Social Inclusion/Exclusion which is, in effect, participation. Therefore the readers are encouraged to select tools based on content that is likely to be the most informative for their impact evaluation, rather than the overall concept that is reported to be measured.

6.4. Guidance on conducting impact assessments

In conducting this review a number of interesting findings have arisen which may help to guide CBM in future research directions:

- Our review suggests that studies investigating the impact of rehabilitation in LMICs to date are biased towards interventions for adults with mental illness in Asia. There appears to be a gap in research evaluating interventions for CWDs in LMICs, and people of all ages with impairments other than mental and physical.
- There are also concerns about the quality of the impact assessments undertaken to date. About a third of impact evaluations performed are not designed to test or prove whether the intervention of interest that has brought about an observed change in outcome. They are case-studies with no control groups and therefore attribution of improvements to the programmes cannot be proven.
- Very few impact assessments have been undertaken to assess CBR activities.

There is therefore a great need for high quality impact assessment, particularly those that assess the range of impairments, focus on children and/or on CBR.

When undertaking an impact assessment we recommend the following points.

Planning: Impact assessments should be planned early, ideally from the inception of the activities to be assessed, so that their design can be integrated within the design of the intervention. This will allow inclusion of an appropriate control group, as well as assignment of sufficient budget to the impact assessment. The impact assessment needs to have a clear purpose, which will guide its design.

Design: We recommend that the impact assessment is designed carefully. You will need to consider the following points: a) study design, b) sample size, c) impact assessment tools used, d) follow-up period. Ideally, researchers should be involved at this stage to ensure that the study design is appropriate and the sample size is sufficient. This review has provided recommendations about the impact assessment tools to use. You will need to select these as appropriate for your setting and for the purpose of the impact assessment. It is likely that in some countries (where tools have not already been developed and validated) you will need to cross-culturally adapt tools in the preliminary stages, and the resources (time and skills) in doing this should not be underestimated. It is recommended that multiple tools are used within the impact assessment (e.g. activities, quality of life and poverty) to assess impact on the full range of domains, and for triangulation of evidence. You may also wish to consider including condition-specific tools in addition to generic tools. Clinical tests and functional assessment tools have traditionally been used in impact assessments and these should be included wherever appropriate.

Analysis: The data collected need to be analysed so that the impact of the intervention can be assessed. This analysis will require the data to be entered into a database, cleaned and analysed using statistical methods. It is recommended that researchers are involved at this stage to provide guidance on these issues. It is best to outline the analyses with the researchers before starting the study, to make sure that all the necessary data are collected.

Feedback of results: Impact assessments are undertaken to improve the quality of interventions for people with disabilities. It is therefore important that the results of the assessment are fed back to the stakeholders and clients at all levels, to make sure that change can be implemented. Usual methods for feedback are through organizing planning workshops and through preparing reports for dissemination.

7 ACKNOWLEDGEMENTS

Thank you to IDDC and experts in disability and outcomes impact evaluation who have contributed knowledge and contacts to this review. We would also like to thank CBM for their support of this and other research projects at LSHTM.

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9. APPENDICES

APPENDIX A: Strategy 1 Search (exemplified in Medline via Ovid)

- 1 (individuals or people or persons or adults or children or adolescents or toddlers or infants or population or populations or patients or users or clients or women).tw.
- 2 (impair\$ or disab\$ or handicap\$ or blind or blindness or deaf or deafness or dumb or mental-illness or mental-health or epilep\$ or cerebral-pals\$).tw.
- 3 ((individuals or people or persons or adults or children or adolescents or toddlers or infants or population or populations or patients or users or clients or women) adj4 (impair\$ or disab\$ or handicap\$ or blind or blindness or deaf or deafness or dumb or mental-illness or mental-health or epilep\$ or cerebral-pals\$)).tw.
- 4 (impact or effectiveness or evaluation or evaluations or evaluating or outcome or outcomes or follow-up).ti.
- 5 (Community-based-rehabilitation or community-rehabilitation).tw.
- 6 (rehabilitation or rehabilitative or intervention or interventions or service or services).tw.
- 7 impact assessment.tw.
- 8 (Asia\$ or Africa\$ or South-America\$ or central-america\$ or latin-America\$ or west-indies or caribbean or ((developing or underdeveloped or low-income or resource-poor or middle-income or third-world or majority-world) adj1 (countr\$ or nation\$))).tw.
- 9 (Tajikistan or tadzhik\$ or uzbek\$).tw.
- 10 exp Disabled Persons/
- 11 Developing Countries/ or exp caribbean region/ or exp central america/ or latin america/ or exp south america/ or exp asia/ or africa/ or exp "africa south of the sahara"/
- 12 Uzbekistan/ or Tajikistan/
- 13 2 and 7
- 14 4 and 5
- 15 4 and 6 and (3 or 10) and (8 or 11)
- 16 4 and 6 and (3 or 10) and (9 or 12)
- 17 13 or 14 or 15
- 18 16 or 17
- 19 limit 18 to english language
- 20 limit 19 to yr="1990 - 2010"

APPENDIX B: Strategy 3 Search (exemplified in Medline via Ovid)

- 1 (Health-related-quality-of-life or HRQL or HRQOL or quality-of-life or QOL or health status or wellbeing or wellbeing or disability or functional status or participation or activities or activity or ADL or social-functioning or psychosocial-functioning).ti,ab.
- 2 (generic or chronic or disab\$).ti,ab.
- 3 (developing or development or valid\$ or reliab\$ or psychometric\$).ti.
- 4 (questionnaire\$ or tool\$ or instrument\$ or index or survey\$ or profile\$ or scale\$ or assessment\$ or score\$ or measure\$ or inventory or inventories).ti.
- 5 1 and 2 and 3 and 4
- 6 limit 5 to (english language and yr="2000 - 2010")

