

Effectiveness of interventions for people with disabilities in low- and middle-income countries: an evidence and gap map

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SCOPE OF THE EVIDENCE AND GAP MAP

Full name: The effectiveness of interventions for people with disabilities in low- and middle-income countries: an evidence and gap map

Short name: Interventions for people with disabilities in low- and middle-income countries: an evidence and gap map

Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. The Preamble to the United Nation Convention on the Rights of Persons with Disability (UNCRPD) acknowledges that disability is “an evolving concept”, but also stresses that “disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others”. An impairment becomes disabling when individuals are prevented from participating fully in society because of social, political, economic, environmental or cultural factors.

The map will cover broad range of interventions for disabilities in children, adults and elderly described as having disabilities and it will have a major focus on persons with disabilities in vulnerable situations.

BACKGROUND

More than 1 billion persons in the world have some form of disability. This corresponds to about 15% of the world's population (World Report on Disability, 2011). There is higher disability prevalence (80%) in Low and Middle Income Countries (LMICs) than high income countries, and disability is believed to affect disproportionately the most disadvantaged sector of the population (Banks, Kuper, & Polack, 2017) (Alavi, Kuper, & Patel, 2010). People with disabilities are more likely to experience adverse socioeconomic outcomes than people without disabilities, such as less education, poorer health outcomes, lower levels of employment, lower immunization coverage, low birth weight and higher poverty rates (World Report on Disability, 2011). As stated above, people with disabilities are more likely to experience poverty but being poor also increases the chance of having a disability. ‘Twin-Track approach’, largely accepted by many international donors (for example the World Bank, DFID, the German Cooperation; the EC, the Finnish Cooperation) and NGOs, aims to break this cycle by both empowerment of individuals/families/organisations and by

breaking down barriers in society. It works at mainstreaming disability into every sector and every development action with the overall goal of increasing the general level of awareness.

A range of international documents have highlighted that disability is a human rights issue, including the World Programme of Action Concerning Disabled People (1982) (WPA, 1982), the Convention on the Rights of the Child (1989) (CRC, 1989), and the Standard Rules on the Equalisation of Opportunities for People with Disabilities (1993) and most importantly The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), 2006 (CRPD, 2006). The UNCRPD aims to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”. It reflects the major shift in global understanding and responses towards disability, and emphasises that people with disabilities have the right for full inclusion.

A second key argument for a focus on disability is from a development perspective. There are a large number of people with disabilities, and they are often “Left Behind” in key areas of development, and so the achievement of development goals is unlikely unless programmes are inclusive of people with disabilities. The World Health Organisation’s (WHO) Community Based Rehabilitation (CBR) guidelines is one of the main strategies that addresses and advocates social inclusion. CBR is a multisectoral, bottom-up strategy which can ensure that the Convention on rights of people with disability (CBR: A strategy for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of, 2004) makes a difference at the community level. CBR activities are designed to meet the basic needs of people with disabilities, reduce poverty, and enable access to health, education, livelihood and social opportunities. In recognition the above points, disability is referenced in various parts of the Sustainable Development Goals (SDGs) (Agenda 2030 and SDGs) related to education, growth and employment, inequality, accessibility of human settlements. Furthermore, SDG 17 stresses that in order to strengthen the means of implementation and revitalize the global partnership for sustainable development, the collection of data and monitoring and accountability of the SDGs are crucial. Significantly increasing the availability of high-quality, timely and reliable data that is also disaggregated by disability is one of the key mandates. Evidence and gap maps (EGMs) can contribute to achieving SDG 17 by supporting the prioritization of global evidence synthesis needs and primary data collection.

OBJECTIVE

The proposed evidence and gap map will present studies of the effectiveness of these interventions across a range of outcome domains. Specifically, the objectives of the map are to:

- i. Develop a clear framework of types of interventions and outcomes related to effectiveness of interventions for people with disabilities in low-and middle-income countries.
- ii. Map available systematic reviews and primary studies on the effectiveness of interventions for people with disabilities in low-and middle-income countries in this framework, with an overview provided in a summary report.
- iii. Provide database entries of included studies which summarize the intervention, context, study design and main findings.

EXISTING REVIEWS

Evidence map:

Niall Winters, Laurenz Langer, Anne Geniets. Physical, psychological, sexual, and systemic abuse of children with disabilities in East Africa: Mapping the evidence. *PLoS ONE* 12(9)

Systematic reviews:

Iemmi, Valentina, Lorna Gibson, Karl Blanchet, Suresh Kumar, Santosh Rath, Sally Hartley, Gudlavalleti VS Murthy, Vikram Patel, Joerg Weber, and Hannah Kuper. "Community-based rehabilitation for people with disabilities in low-and middle-income countries: A systematic review." *Campbell Systematic Reviews* 11, no. 15 (2015).

Erik W. Carter, Lynn G. Sisco, Yun-Ching ChungTina L. Stanton-Chapman. Peer Interactions of Students with Intellectual Disabilities and/or Autism: A Map of the Intervention Literature. *Research and Practice for Persons with Severe Disabilities* 2014; 35(3-4): 63–79.

Mikton C, Maguire H, Shakespeare T. A systematic review of the effectiveness of interventions to prevent and respond to violence against persons with disabilities. *Journal of Interpersonal Violence* 2014; 29(17): 3207-26

Nadine Koslowski, Kristina Klein, Katrin Arnold, Markus Kösters, Matthias Schützwoh et al. Effectiveness of interventions for adults with mild to moderate intellectual disabilities and mental health problems: systematic review and meta-analysis. *The British Journal of Psychiatry* May 2016;114.

INTERVENTIONS

As indicated in SDG guidelines to generate an inclusive and global dialogue, implementing the SDGs must be in line with and build upon existing international and national commitments and mechanisms. The WHO's Community Based Rehabilitation (CBR) recognizes CBR as a comprehensive and multi-sectoral strategy to equalize opportunities and include people with disabilities in all aspects of community life. Therefore, the CBR will serve as a guiding framework for the intervention and outcome categories as listed below in order to realize the full inclusion and empowerment of persons with disabilities.

The included interventions cover all main strategies to reduce disability related outcome. The six main intervention categories are:

1. Health
2. Education
3. Livelihood
4. Social
5. Empowerment
6. Advocacy and Governance

Table 1 lists the intervention sub-categories under each of these headings

CBR Pillar (Intervention Category)	Component (Intervention sub-category)	Examples
Health	Promotion	Parent/Family training and education,
	Prevention	Avoidance of war; improvement of the educational, economic and social status of the least privileged groups; identification of types of impairment and their causes within defined geographical areas; introduction of specific intervention measures through better

		nutritional practices; improvement of health services, early detection and diagnosis; prenatal and postnatal care; proper health care instruction, including patient and physician education; family planning; legislation and regulations; modification of life-styles; selective placement services, education regarding environmental hazards; and the fostering of better informed and strengthened families and communities.
	Medical Care	Periodic health screening, evaluation of traumatic injuries
	Rehabilitation	Training in self-care activities, including mobility, communication and daily living skills, with special provisions as needed, e g., for the hearing impaired, the visually impaired and the mentally retarded, Vocational rehabilitation services (including vocational guidance), vocational training, Cognitive Behaviour Therapy, Cognitive stimulation, rehabilitation and training, Activity therapy centres, Supportive therapy, Stress-management interventions/psychosocial support, Interpersonal therapy, modification of environment,
	Assistive devices	Provision of appliances (ortheses, prostheses, hearing aids, etc.), devices such as day calendars with symbol pictures for people with cognitive impairment, communication boards and speech synthesizers for people with speech impairment
Education	Early child development	Speech and language therapist, Physiotherapy, Gait training, occupational therapy Inclusive social services and child protection
	Non-formal	Community based-sports program, faith-based schools, home-based learning, play groups
	Primary Secondary and higher	Inclusive early childhood education Provision of learning material and special equipment (Braille, audio cassettes, sign language, etc.) Recruitment and training of specialized teachers Resource rooms Bypass intervention

	Life-long learning	Explicit social skills interventions
Livelihood	Skills development	Training opportunities for jobs
	Self-employment	Income generation program
	Waged employment	Realistic quota legislation in jobs and Participation in labour intensive public works programs
	Financial services	Access to credit, health insurance coverage
	Social protection	International legislation like universal declaration of human rights, Social insurance schemes, birth registration, social assistance intervention, referral services
Social	Relationship, marriage & family	family planning accessible to disabled, media campaigns, religious leaders
	Personal assistance	Accommodation support, home modifications, self-help groups and disabled people organisation
	Culture, religion and arts	Promoting use of art for social change like positive portrayal, silent theatres, complementary therapy in the form of art, music. Inclusive art education, diversity trainings, Encouraging inclusion in mainstream cultural programmes, Work with spiritual and religious leaders and groups
	Sports, recreation and leisure	Provision of adapted sports equipment, organization of inclusive sports events, linking people with disabilities to mainstream recreation and sporting clubs/associations, positive media coverage of disability recreation, Using recreation and sport to raise awareness about inclusion, advocate alongside disabled people's organizations, appropriate training
	Access to justice	Legal awareness, Identification of available resources like local leaders, DPO's, legal centres, legal aid. Promoting legal rights and empowerment, inheritance right, community or legal aid centre

Empowerment	Social mobilisation	
	Political participation	Reservation of Position in public and political institution
	Language & communication	Speech and language therapy, deaf clubs, stroke clubs, self-advocacy, Interventions removing communication barriers
	Self-help groups & Disabled People's Organizations	Creating joint resources like training material, community directories, advocating rights of persons with disability
Advocacy and Governance		<p>National prevention programs against certain illnesses (polio, leprosy)</p> <p>Establishment/Reinforcement of a Special Education Service in the Ministry of Education</p> <p>Establishment/Reinforcement of medical rehabilitation centres</p> <p>Legislative reforms: elimination of all forms of discrimination</p> <p>Mandating healthy behaviour as Childhood immunization/seat belts etc.</p> <p>Raising awareness on human rights through media</p> <p>Appropriate budgetary allocation</p>

POPULATION

The target population are populations are people with disabilities living in low- and middle-income countries.

Population sub-groups of interest include: women, vulnerable children (particularly children in care), conflict (conflict and post-conflict settings), migrants, and ethnic minority groups.

DIMENSIONS

In addition to intervention and outcomes, the following filters will be coded:

- (1) Population sub-groups of interest include: age group (under-five, children, adolescent and elderly), women, vulnerable children (particularly children in care), conflict (conflict and post-conflict settings), migrants, and ethnic minority groups
- (2) Study designs
- (3) Region
- (4) Country

OUTCOMES

Seven Sustainable Development Goal (SDGs) targets specifically mention persons with disabilities with following indicators education, accessible schools, employment, accessible public spaces and transport, empowerment and inclusion, data disaggregation as focus.

The five main outcome categories are as mentioned below and they are plotted against the WHO's Community Based Outcome Indicator (CBR) indicators:

1. Health
2. Education
3. Livelihood
4. Social
5. Empowerment

Table 2: Outcome categories and sub-categories

Outcome	WHO's Community Based Rehabilitation (CBR) Indicators
Health component	
Mental health and cognitive development	

Access to health services	Men, women, boys and girls with disability equally access health services and engage in activities needed to achieve the highest attainable standard of health
	% of people with disabilities and their families that have access to medical care
	Men, women, boys and girls with disability feel they are respected and treated with dignity when receiving health services
Immunization	% of people with disabilities who receive full immunization as recommended for their country by WHO
Health check-up	Men, women, boys and girls with disability know how to achieve good levels of health and participate in activities contributing to their health
	% of children with disability who receive the recommended health check-ups
Rehabilitation services	Men, women, boys and girls with disability engage in planning and carry out rehabilitation activities with the required services
Access to assistive devices	Men, women, boys and girls with disability have access to, use, and know how to maintain appropriate assistive products in their daily life
Nutrition	
Morbidity and mortality	Men, women, boys and girls with disability access and benefit from quality medical services appropriate to their life stage needs and priorities
Education	
Enrolment to primary, secondary and tertiary education	Policies and resources are conducive to education for people with disabilities and ensure smooth transitions through different stages of learning
	Children with disability participate in and complete quality primary education in an enabling and supportive environment
	Men, women, boys and girls with disability have resources and support to enrol and complete quality secondary and higher education in an enabling and supportive environment
	Youth with disability experience post school options on an equal basis with their peers

Attendance	Men, women, boys and girls with disability have resources and support to enrol and complete quality secondary and higher education in an enabling and supportive environment
Education in mainstream education facilities/inclusive education	% of people with disabilities who acquire education in mainstream education facilities
Social and life skill development	Men, women, boys and girls with disability make use of youth or adult centered learning opportunities to improve their life skills and living conditions
learning and achievement	Men, women, boys and girls with disability experience equal opportunities to participate in learning opportunities that meet their needs and respect their rights
Access to educational services	Children and youth with disability participate in a variety of non-formal learning opportunities based on their needs and desires
	Children with disability actively participate in early childhood developmental activities and play, either in a formal or informal environment
Livelihood	
Employment in formal and informal sector	Men and women with disability have paid and decent work in the formal and informal sector on equal bases with others
	Women and men with disability earn income through their own chosen economic activities
	Youth and adults with disability acquire marketable skills on an equal basis with others through a range of inclusive training opportunities
Access to job market	
Control over own money	Women and men have control over the money they earn
Access to financial services such as grants and loans	Men and women with disability have access to grants, loans and other financial services on an equal basis with others
	Men and women with disability participate in local saving and credit schemes
Poverty and out-of-pocket payment	% of people with disabilities who are covered by social protection programs

Access to social protection programs	Men and women with disability access formal and informal social protection measures they need
Participation in development of inclusive policies	Inclusive policies, practices and appropriate resources, defined with PwD, enable equal participation of women and men with disability in livelihood (training, finance, work opportunities and social protection)
Social	
Stigma and discrimination	
safety	Men, women, boys and girls with disability feel safe in their family and community
Participation in mainstream recreational, leisure and sports activity	Men, women, boys and girls with disability participate in inclusive or specific recreation, leisure and sports activities
legal rights	All PwD are recognized as equal citizens with legal capacity
Access to justice	PwD access and use formal and informal mechanisms of justice
Participation in cultural and religious activity	Men, women, boys and girls with disability participate in artistic, cultural or religious events in and outside their home as they choose
Interpersonal interaction and relationships	Men, women, boys and girls with disability experience support of the community and their families to socialize and form age-appropriate and respectful relationships
	% of people with disabilities who feel respected in their decisions regarding personal relationships
Social identity and responsibilities	Men, women, boys and girls with disability feel valued as community members and have a variety of social identities, roles and responsibilities
Empowerment	
Informed choices	PwD make informed choices and decisions
Positions in public institutions and Judiciary	Men and women with disability participate in political processes on an equal basis with others

Voting rights	Men and women with disability participate in political processes on an equal basis with others
Representation at community level	PwD actively engage in and benefit from self-help groups in the local communities, if they choose (inclusive or specific)
	Self-help groups come together to form federations to harness collective energy and influence positive change
	Men and women with different kinds of disability living in different situations (rural or urban areas, poor or rich, refugees) feel they are adequately represented by DPO
Advocacy	Men, women, boys and girls with disability effectively use communication skills and resources (including supportive decision making) to facilitate interactions and influence change
	Men, women, boys and girls with disability play a catalyzing role in mobilizing key community stakeholders to create an enabling environment

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STUDY DESIGNS

The EGM will include effectiveness studies and systematic reviews of effects of interventions.

PROCESS FOR DEVELOPING THE FRAMEWORK

The framework will be developed through the following process:

Stage 1: Initial framework to be constructed through review of strategy and policy documents

Stage 2: Discussion through external consultation through: (i) meeting of subject experts in the area of disability from India, London and Nepal (ii) webinar/online feedback Campbell experts on disability (iii) consultation with DFID staff (iv) NGOs working on disability and persons with disability will be the key stakeholders.

Stage 3: Piloting framework with 15 included studies. The framework will be finalized once the first 15 studies are coded. The protocol will be revised at that point.

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Alavi, Y., Kuper, H., & Patel, S. (2010). *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*. London School of Hygiene & Tropical Medicine, UK/CBM, Germany.

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ROLES AND RESPONSIBILITIES

- ***Content expertise:***

Dr Hannah Kuper, Director of the International Centre for Evidence in Disability, a research group at LSHTM that works to expand the research and teaching activities of LSHTM in the field of global disability. Her main research interest is disability in low and middle income countries, with a particular focus on assessment of the prevalence of disability and impairments, including in children, and development of new methods in undertaking these surveys (e.g. use of mobile technologies), investigation of the health and rehabilitation needs of people with disabilities, and how these can be met in low resources settings and research on the relationship between poverty and disability, and the potential role of social protection in breaking this cycle. She has an undergraduate degree from Oxford University in Human Sciences and a doctorate from Harvard University in epidemiology. She has worked at LSHTM since 2002.

- ***EGM method expertise:***

All team members have previous experience in systematic review methodology, including search, data collection, statistical analysis, theory-based synthesis, which mean they are proficient in carrying out the various processes in an EGM, such as search, eligibility screening, quality assessment and coding.

- ***Information retrieval expertise:***

All authors have previous experience in developing search strategies.

FUNDING

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POTENTIAL CONFLICTS OF INTEREST

No conflicts of interest.

PRELIMINARY TIMEFRAME

Phase 1: Systematic reviews

- 25 January 2018: Protocol and Literature search completed
- 15 February 2018: Study inclusion completed
- 28 February 2018: Quality assessment and coding completed
- 15 March 2018: Draft EGM submitted
- 31 March 2018: Final EGM submitted

Phase 2: Primary studies

- 25 January 2018: Protocol and Literature search completed
- 15 February 2018: Study inclusion completed
- 28 February 2018: Quality assessment and coding completed
- 15 March 2018: Draft EGM submitted
- 31 March 2018: Final EGM submitted