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# Community-based rehabilitation for people with disabilities

March 2016

Systematic Review Summary 4







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Community-based rehabilitation for people with disabilities, 3ie Systematic Review Summary 4, is a summary of the full review, Community-based rehabilitation for people with disabilities in low- and middle-income countries: a systematic review, which is available with all of its appendixes on the 3ie <u>website</u>.

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Suggested citation: Iemmi, V, Kuper, H, Blanchet, K, Gibson, L, Kumar, KS, Rath, S, Hartley, S, Murthy, GVS, Patel, V, and Weber, J, 2016. *Community-based rehabilitation for people with disabilities, 3ie Systematic Review Summary 4*. London: International Initiative for Impact Evaluation (3ie).

## **3ie Systematic Review Summary Series executive editors**: Edoardo Masset and Beryl Leach

Managing editor: Deepthy Menon Contributing editors: Stuti Tripathi and Hugh Waddington Production manager: Pradeep Singh Copy-editing and proofreading: Scriptoria Design: John F McGill Printer: VIA Interactive Cover photo: DFAT

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## Community-based rehabilitation for people with disabilities

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## 3ie Systematic Review Summary 4 March 2016



## Acknowledgements

This review was supported by a grant from the International Initiative for Impact Evaluation (3ie). We thank the Campbell Collaboration (International Development Coordinating Group) for assistance throughout the review process.

The authors of the review would like to thank Chapal Khasnabis (World Health Organization), Elena Schmidt (Sightsavers), Philippe Chervin (International Foundation of Applied Disability Research), Richard Wormald (London School of Hygiene & Tropical Medicine), Susie Miles (Manchester Institute of Education), Sue Lukersmith (University of Sydney), Harry Finkenflügel and all the experts and authors we contacted for their valuable support, and Alejandra Hernandez for help with translations.

## Summary

There are an estimated one billion people with disabilities globally, corresponding to about 15 per cent of the world's population (WHO 2011). Among them, 80 per cent of people with disabilities live in low- and middle-income countries.

People with disabilities include those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (UN 2008; WHO 2011). People with disabilities are often excluded from education, health, employment and other aspects of daily life, and are generally poorer. It is therefore widely argued that the Millennium Development Goals and the post-2015 targets cannot be achieved without integrating disability issues into the agenda.

We conducted a systematic search for evidence on the effects of community-based rehabilitation (CBR) on health, education, livelihoods, social and empowerment outcomes.

### The intervention

Community-based rehabilitation is a strategy for general community development that provides rehabilitation, poverty reduction, equalisation of opportunities, and social inclusion for all people with disabilities. It is designed predominantly for low- and middle-income countries. It aims to meet the needs of people with disabilities with respect to health, education, livelihood, social and empowerment issues (WHO 2010). CBR is delivered at the community level, primarily through local resources. Examples include promoting inclusive education, teaching parents to provide treatment to their child, or creating self-help groups.

CBR is the strategy endorsed by the World Health Organization and other international organisations for general community development that provides rehabilitation, poverty reduction, equalisation of opportunities, and social inclusion for all people with disabilities. It is designed predominantly for low- and middle-income countries.

#### Implementation evidence

This review includes evidence from:

Six studies assessing the effectiveness of CBR for people with physical disabilities

 specifically, people after stroke, with arthritis and with chronic obstructive
 pulmonary disease. These studies were conducted in China, Indonesia, Iran,
 Turkey and Thailand; and

• Nine studies exploring the impact of CBR on the lives of people with mental disabilities – schizophrenia, dementia and intellectual impairment. These studies were conducted in China, India, Peru, Russia, South Africa and Vietnam.

The evidence was provided in these studies on a broad range of outcomes – including activities, clinical status, quality of life, use of health resources and a reduction in adverse effects – measured in the short and medium term.

The available evidence is limited to people with specific types of physical and mental disabilities and intellectual impairments, with no evidence for people with sensory impairments (hearing and visual). All studies were undertaken in Asia with only one study from Africa. Except for one study on children, the evidence focuses on adults and elderly people.

#### Findings

Overall, the majority of studies suggested that CBR was an effective strategy for improving the lives of people with disabilities and their families. The evidence suggests that CBR improved clinical outcomes and enhanced functioning and quality of life of the people with disabilities. The studies also showed a modest beneficial impact on their families in terms of improving quality of life and reducing the burden of giving care.

There is limited evidence suggesting a positive impact of CBR for stroke survivors. The interventions assessed were home healthcare and rehabilitation in Thailand (Chinchai *et al.* 2010), planned self-care home-based education in Iran (Habibzadeh *et al.* 2007), home-based rehabilitation in China (Yu *et al.* 2009) and CBR in Turkey (Ozdemir *et al.* 2001). For arthritis, the evidence is based on only one study suggesting a positive impact of CBR on improving knowledge about arthritis, implemented through community education by traditional puppet shadow play in Indonesia (Darmawan *et al.* 1992). For people living with chronic obstructive pulmonary disease, the evidence is based on only one study reporting a positive effect of community-based group education in Thailand (Noonill *et al.* 2007).

There is limited evidence suggesting a positive impact of CBR for people with schizophrenia. This includes assertive community treatment in South Africa (Botha *et al.* 2010), psycho-educational family intervention (Ran *et al.* 2003) and group counselling (Zhang *et al.* 1994b; 1998) in China, and CBR in India (Chatterjee *et al.* 2003). The evidence on family members is based on one study suggesting a positive impact of group counselling on family members of people living with schizophrenia in China (Zhang *et al.* 1994b; 1998). Three studies suggested a positive impact of a flexible stepped home-care programme for families of people with dementia in India (Dias *et al.* 2008), Peru (Guerra *et al.* 2011) and Russia (Gavrilova *et al.* 2009). One single study suggested a positive impact of CBR in the lives of children with intellectual impairment in Vietnam (Shin *et al.* 2009).

However, there are important gaps in our understanding of the impact of CBR in the lives of people with disabilities. These gaps in the evidence base limit the strength of our results.

CBR is intended as a strategy for people with all types of disabilities, yet the studies mostly focused on a few physical (stroke, arthritis and chronic obstructive pulmonary disease) and mental health conditions (schizophrenia and dementia) and intellectual impairment, and did not include any people with sensory impairments (hearing or visual). Furthermore, except for one study on children, the evidence mainly focuses on adults and elderly people.

CBR was developed as an approach for providing services to people with disabilities in low- and middle-income countries. However, the geographical coverage of the evidence is very restricted, with most studies from Asia, particularly China, and only one from Africa, despite the large emphasis on implementation of CBR programmes on that continent.

#### Implications for policy, practice and research

Overall, the available studies show consistent evidence for a positive impact of CBR in the lives of people with disabilities and their families. However, the evidence base is currently scarce and based on few robust studies. There is a need for further and good-quality evidence to close the evaluation gap.

New studies should be designed to target specific gaps in the available evidence. These studies should capture the full impact of CBR, evaluating CBR programmes targeting the cross-cutting needs of people with disabilities in the areas of health, education, livelihoods, social inclusion and empowerment rather than focusing heavily on health. Furthermore, the studies should reflect the usual client group for CBR, beyond people with specific types of physical and mental disabilities, adults or elderly people only. More studies are needed to evaluate the effectiveness of CBR within all low- and middle-income countries, particularly in Africa where a variety of CBR programmes have been implemented.

New studies should adopt more robust methodologies to build a stronger evidence base. In particular, study designs like randomised controlled studies, and larger sample sizes should be ensured to produce reliable results.

Studies on the cost-effectiveness of CBR are necessary to support the scaling up of CBR programmes by identifying areas needing investment.

Undertaking these studies will be difficult due to the complexity of CBR, the variety of disabilities and the additional challenge in undertaking research in low- and middleincome countries. Notwithstanding these challenges, strengthening the evidence base for CBR is crucial to inform the decisions of practitioners and policymakers and to facilitate more effective and cost-effective implementation of CBR.

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## Abbreviations and acronyms

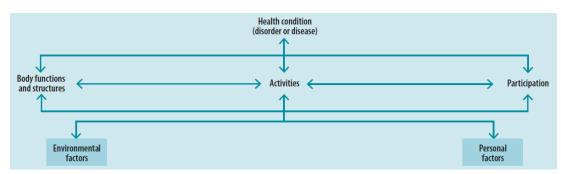
ADL	activities of daily living
CBR	community-based rehabilitation
COPD	chronic obstructive pulmonary disease
ICF	International Classification of Functioning, Disability and
	Health
IDDC	International Disability and Development Consortium
ILO	International Labour Organization
RCT	randomised controlled trial
UN	United Nations
UNESCO	United Nations Educational, Scientific and Cultural Organization
WHO	World Health Organization

## 1. Global disability: magnitude and impact

There are over one billion people with disabilities in the world (WHO and World Bank 2011). This corresponds to about 15 per cent of the world's population, and 80 per cent of these people live in low- and middle-income countries. People with disabilities include those who have long-term physical, mental, intellectual or sensory impairments, which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others (UN 2008).

The International Classification of Functioning, Disability and Health (ICF) conceptual framework illustrates this view of disability (Figure 1). According to this model, a health condition may lead to an impairment. For instance, polio can lead to muscle weakening and consequently to physical impairment. A cataract causes clouding of the lens in the eye and then visual impairment. Dementia is caused by brain damaging diseases, which cause cognitive impairment.

Impairment may lead to reduced activities. In the previous examples, polio may lead to difficulties in walking, cataract in self-care and mobility, and dementia in self-care. These limitations in activities can restrict full participation in aspects of society, such as exclusion from employment or education, thus resulting in disability.



## Figure 1: International Classification of Functioning, Disability and Health conceptual framework

#### Source: WHO (2011, Box 1.1, page 5)

The impact of a health condition on disability is not the same for everyone and is influenced by a variety of factors. One factor is the availability of medical treatment. For instance, treatment of a cataract can fully correct a visual impairment and avoid disability. People may have impairments that are not amenable to medical treatment (e.g. irreversible paralysis) or not have access to services, in which case personal factors may mitigate the negative consequences of the impairment (e.g. additional training could enhance employment prospects). Environmental changes, such as the provision of technological devices (e.g. mobility aids and hearing aids) or adaptations to buildings can also improve participation among people with impairments, thus alleviating disability.

The ICF conceptualisation of disability is therefore an expansion beyond the limited medical view, which focuses on impairments only as the cause of disability.

Disability is often viewed as both a cause and a consequence of poverty. Poorer people, and people living in poorer countries, are more vulnerable to disability (WHO and World Bank 2011). Furthermore, people with disabilities are excluded from education, health, employment and other aspects of society, and this can potentially lead to or exacerbate poverty (WHO and World Bank 2011). As an example, a recent report across 30 countries found that children with disabilities were often 10 times less likely to attend school than their peers without disabilities, and even when enrolled at school they were often at a lower education level (Kuper *et al.* 2014). These exclusions are contrary to the United Nations (UN) Convention on the Rights of Persons with Disabilities, which is an international human rights instrument of the UN intended to protect the rights and dignities of people with disabilities (UN 2008). A focus on disability is therefore important both from an international development and a human rights perspective. More information is needed as to which interventions are effective at enhancing participation in society by people with disabilities.

One approach to addressing disability is community-based rehabilitation (CBR), which has received high-level endorsement and is implemented throughout the world. CBR is a strategy for general community development that provides rehabilitation, poverty reduction, equalisation of opportunities and social inclusion for all people with disabilities.

However, establishing an evidence base for the impact of CBR has been difficult (Hartley *et al.* 2009). Each individual programme is tailored to the specific user needs and setting and therefore includes a different focus and different components. Furthermore, the impact of CBR can be measured in a variety of ways (e.g. participation, quality of life and clinical outcomes). Consequently, the evidence base is qualitatively rich and quantitatively poor and a comprehensive systematic review has not previously been undertaken<sup>1</sup>.

<sup>&</sup>lt;sup>1</sup> The most extensive previous review of CBR included 128 articles published between 1978 and 2002, only 10 of which were classified as intervention studies (Finkenflugel, Wolffers and Huijsman 2005). The authors did not assess the overall impact of CBR in their review and concluded that "the evidence base for CBR is fragmented and incoherent on almost all aspects of CBR". Other reviews have reported more positively on the literature, but were more limited in scope. One identified 29 reports on rehabilitation in community programmes in low- and middle-income countries (Velema, Ebenso and Fuzikawa 2008). The studies were small, and had methodological limitations, but showed that these programmes were broadly effective. Reviews have also assessed the effectiveness of CBR for specific types of disability. Wiley-Exley (2007) identified 17 intervention studies evaluating community mental healthcare in low- and middle-income countries. These interventions improved mental health outcomes and were cost saving (where this was assessed), but only one of the interventions was described as CBR (Chatterjee et al. 2003). Another review of 11 studies assessing CBR programmes for adults with traumatic brain injury also found evidence for effectiveness (Evans and Brewis 2008).

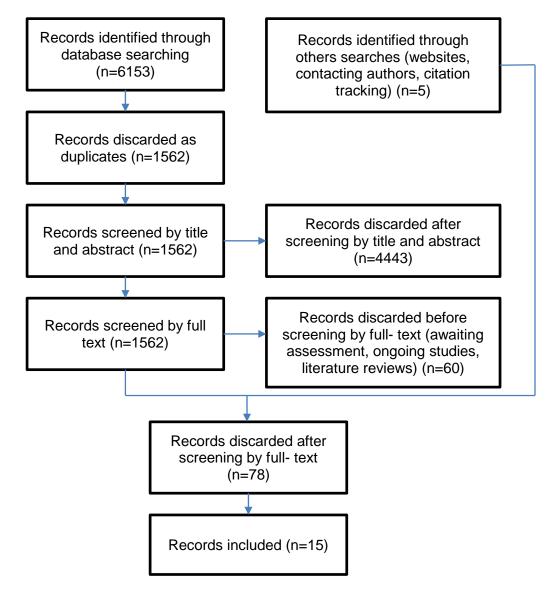
This report provides a summary of a full systematic review of evidence from impact evaluations on the effectiveness of CBR interventions to improve outcomes for people with disabilities (lemmi *et al.* 2015). Evidence eligible for the review came from controlled studies where CBR was offered to people with disabilities and/or their family, carers or community in low- and middle-income countries. Any CBR intervention was eligible for the review, whether targeting health, education, livelihood, social or empowerment components of disability, provided the intervention took place in households or the community; we excluded studies where CBR interventions took place only in health facilities or schools.<sup>2</sup>

Extensive searches for published and unpublished literature were conducted, from 23 electronic databases, including studies published after 1976 and up until July 2012, and also using websites, author contacts, screening of reference lists and citation tracking of included studies. We identified 6,157 records, of which 148 were considered sufficiently relevant to CBR as to screen as full text. Finally, a total of 15 studies were deemed of sufficient quality for inclusion in the review (Figure 2).

The report is structured as follows. Chapters 2 and 3 provide background on CBR and the causal chain through which CBR is expected to work. Chapter 4 presents implementation experiences, drawing on the studies included in this review and additional sources of evidence. Chapter 5 presents the results of impact assessments from the included studies. The final chapter gives implications for policy and research.

<sup>&</sup>lt;sup>2</sup> We used a broad definition of CBR in order to maximise the usefulness of the limited data available. Consequently, some interventions were included which arguably could be classified as home-based care programmes, rather than CBR. However, using a more restrictive definition of CBR or disability would have substantially reduced the pool of eligible publications found during the searches and our ability to make inferences as to the effectiveness of CBR.





## 2. Community-based rehabilitation

A wide range of potential interventions exist that can enhance the participation and quality of life of people with disabilities. Few such services are available in low- and middle-income countries. Consequently, alternative strategies must be sought in these areas.

CBR is the strategy endorsed by the World Health Organization (WHO) for the rehabilitation, poverty reduction, equalisation of opportunities and social inclusion of all people with disabilities (WHO 2010). It is designed predominantly for low- and middle-income countries.

CBR was first introduced in the late 1970s (WHO 1976; 1978; Finkenflugel 2004). Early programmes mostly focused on physiotherapy, assistive devices and medical interventions. The concept has evolved over the last 30 years so that CBR has become a strategy for community-based inclusive development. CBR is used to meet the basic needs of people with disabilities and their families and to enhance their quality of life.

The CBR matrix (WHO 2010) (see Figure 3) provides a basic framework for CBR programmes. It highlights the need to target intervention in five key components: health, education, livelihood, social and empowerment. Each component includes five elements where the different activities are listed. A CBR programme is formed by one or more activities in one or more of the five components. The focus can be on providing new services as well as promoting inclusion of people with disabilities into existing services. Each CBR programme is not expected to implement every component of the CBR matrix, but will vary depending on the needs of their users. CBR programmes are therefore very diverse.

This diversity and flexibility in intervention is in keeping with the conceptualisation of disability through the ICF model, which recognises the range of influences on disability. Consequently, a range of interventions can be implemented to alleviate disability and enhance quality of life.

CBR is implemented through the combined efforts of people with disabilities, their families and communities, and the relevant services (ILO, UNESCO and WHO 2004). CBR is delivered within the community using predominantly local resources, to ensure that the interventions are locally appropriate and low cost. CBR is therefore a multisectoral, 'bottom-up' strategy.

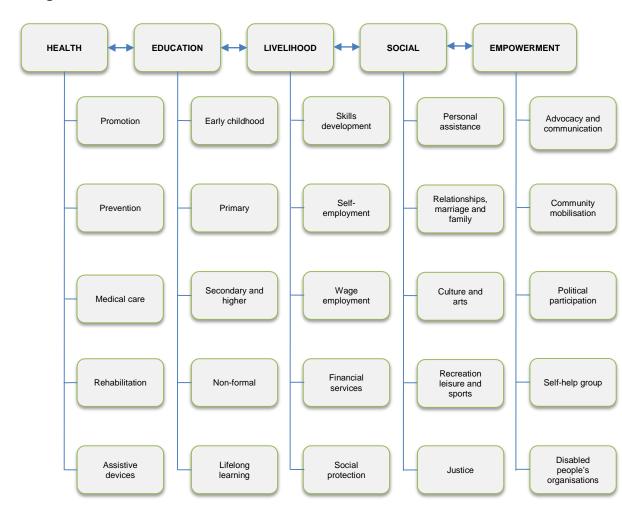


Figure 3: The CBR matrix

Source: WHO (2010, Figure 1)

The CBR guidelines were launched in October 2010 to provide further direction on how CBR programmes should be developed and implemented (WHO 2010). Although CBR is currently implemented in over 90 countries, in reality, few disabled people are believed to have access to even basic health and rehabilitation services (Meikle 2002). The scaling up of CBR is therefore urgently needed, but there is also a need for a stronger evidence base on the efficacy and effectiveness of CBR programmes to support an expansion in their coverage (Finkenflugel, Wolffers and Huijsman 2005; Hartley *et al.* 2009; WHO and World Bank 2011).

## 3. How CBR is meant to work

The overall aim of CBR is to improve the quality of life of people with disabilities and their families. CBR is meant to work by including people with disabilities in existing services, as well as creating new interventions specifically targeting people with disabilities and their families. The causal chain for these interventions is described in Figure 4, and is illustrated with examples below.

The goal of the *health* component is that people with disabilities achieve their highest attainable standard of health. It includes the following:

- promotion (e.g. providing messages specifically to people with disabilities or ensuring that ongoing health promotion efforts are inclusive of people with disabilities)
- prevention (e.g. preventing impairments or preventing illness among people with disabilities)
- medical care (e.g. collaborating with local healthcare facilities in the community to ensure that they are inclusive and accessible to people with disabilities)
- rehabilitation (e.g. practising mobility exercises and adapting the physical environment)
- provision of assistive devices (providing locally made and appropriate mobility and other aids).

These interventions therefore target improvements in knowledge, health and clinical outcomes, and reduced impairments.

The goal of the *education* component is that people with disabilities access education and lifelong learning, leading to fulfilment of their potential, a sense of dignity and self-worth, and effective participation in society. This component focuses on increasing attendance and duration of schooling by people with disabilities as well as increasing participation in non-school education. Examples include working together with teachers in the local community to make appropriate adaptations (e.g. accessible toilets and specialised teaching assistants) that allow children to attend school, or providing retraining opportunities for people who develop disability later in life (e.g. teaching Braille).

The *livelihood* component of the CBR matrix has the goal that people with disabilities can gain a livelihood, have access to social protection measures and be able to earn enough income to lead dignified lives and contribute economically to their families and communities. This component focuses on increasing inclusion in employment and enhancing earning abilities for people with disabilities and their families. This could include:

- skills development (e.g. computer training)
- financial services (e.g. microcredit schemes for people with disabilities)

- promotion of wage employment (e.g. apprenticeships or internships for people with disabilities)
- social protection programmes (e.g. disability pensions or other benefit schemes).

The goal of the *social* component is that people with disabilities have meaningful social roles and responsibilities in their families and communities, and are treated as equal members of society. It focuses on improving social participation and improving relationships. This can be achieved through:

- counselling to improve relationships and family life
- challenging negative attitudes and violence against people with disabilities
- personal assistance to participate in family and community life, to support self-care and maintain dignity
- encouraging the inclusion of disabled people in culture and arts, leisure and sports (e.g. inclusive dance groups and art groups for people with dementia)
- access to justice (e.g. providing information to people with disabilities and their families about their rights and how to turn to the justice system).

The goal of the *empowerment* component is that people with disabilities and their family members make their own decisions and take responsibility for changing their lives and improving their communities. This component concentrates on the importance of empowering people with disabilities, their family members and communities to facilitate the mainstreaming of disability across all sectors and to ensure that everybody is able to access their rights. It includes:

- enhancing communication (e.g. providing regular information on CBR programmes and emphasising benefits to the whole community)
- facilitating social mobilisation to get disability into the social consciousness of the community (e.g. through community parties)
- enabling the political participation of people with disabilities in different levels of the political system (e.g. encouraging people with disabilities to stand for elections and lobbying for policy change)
- developing self-help groups to allow information sharing and support among people with disabilities and their families
- establishing disabled people's organisations (DPOs) to advocate for inclusion and change.

Assessing the difference that CBR interventions can make to these outcomes, including for participants and family members or carers, is vital in demonstrating the impacts of CBR.

Intervention			Community-based rehabilitation		
Component	Health	Education	Liv <u>elih</u> ood	Social	Empowerment
Short-term	Improved knowledge	Increased school	Inclusion in employment	Improved social	Improved
outcomes	about health	attendance		participation	community
			Access to skills development		participation
	Improved access to	Improved quality of	and learning	Improved	
	health and	education		relationships	Improved
	rehabilitation services		Enhanced earning		communication
			possibilities	People with	
				disabilities valued	Barriers removed
Intermediate	People with	People with disabilities	People with disabilities gain a	People with	People with
outcomes	disabilities achieve	access education and	livelihood, have access to	disabilities have	disabilities and their
	their highest	lifelong learning,	social protection measures	meaningful social	family members
	attainable standard of	leading to fulfilment of	and are able to earn enough	roles and	make their own
	health	potential, a sense of	income to lead dignified lives	responsibilities in	decisions and take
		dignity and self-worth,	and contribute economically	their families and	responsibility for
		and effective	to their families and	communities, and	changing their lives
		participation in society	communities	are treated as equal	and improving their
				members of society	communities
Longer-term					
outcomes		Improved quality of life for	people with disabilities, their familie	s, and their communities	$\checkmark$

## Figure 4: Causal chain for the impact of community-based rehabilitation programmes for people with disabilities

## 4. Implementation experience

The theoretical foundation of CBR is well developed, with buy-in from key stakeholders including the WHO, the International Labour Organization (ILO), the United Nations Educational, Scientific and Cultural Organisation (UNESCO) and the International Disability and Development Consortium (IDDC). CBR projects have been implemented on a large scale across low- and middle-income countries.

In the systematic review, we identified 15 programmes operating in low- and middleincome countries. The majority of studies took place in Asia (Table 1). Nine of the studies included people with mental disabilities, while the remaining six studies focused on people with physical disabilities. There were no studies including individuals where the disability was due to a sensory impairment (vision or hearing).

However, there are several constraints faced in scaling up access to CBR and compliance with the intended design. There have been few evaluations of CBR (Coernielje *et al.* 2008; Grandisson *et al.* 2014), but the following constraints are evident in these evaluations and in our own field experience:

- 1. Lack of funding for the support of CBR projects (Hartley *et al.* 2009). Where funding is available this is often not sufficiently stable to plan for the long term, and once the non-governmental organisation removes the funding the CBR programme is usually not sustainable.
- 2. Lack of training of CBR field workers (Lorenzo 1994; Maclachlan *et al.* 2010). This reduces their effectiveness when working in complex domains such as health or education and leads to low recognition by other professionals. This issue is further enhanced by the low level of education of most CBR workers.
- Stigma and discrimination against people with disabilities (WHO and World Bank 2011). These factors may lead to low awareness of disability, low uptake of services and low community support of CBR programmes.
- 4. Lack of access to specialist services (WHO and World Bank 2011). CBR workers may wish to refer users to specialised institutions (e.g. schools and rehabilitation centres), but these are often not available in their locality. Similarly, the specialists who give expert advice on particular issues (e.g. doctors and social workers) are often not available in CBR settings. A lack of access to assistive devices and other environmental supports also hampers the implementation of CBR.

The implementation experience of CBR therefore often does not live up to the ambitions of the theoretical conceptualisation.

Author, publication year	Country of study	Type of disability	Type of condition/ impairment	Target group	Number of participants	Follow-up	Primary component of CBR matrix assessed
Randomised control	lled studies						4000000
Chinchai 2010	Thailand	Physical	Stroke	Adults	60	2 months	Health
Yu 2009	China	Physical	Stroke	Adults	737	5 months	Health
Noonill 2007	Thailand	Physical	COPD	Adults	88	3 months	Health
Botha 2010	South Africa	Mental	Schizophrenia	Adults	60	12 months	Health
Ran 2003	China	Mental	Schizophrenia	Adults	357	9 months	Health
Zhang 1994	China	Mental	Schizophrenia	Adults	83	18 months	Health
Dias 2008	India	Mental	Dementia	Older people	81	6 months	Health
Gavrilova 2009	Russia	Mental	Dementia	Older people	60	6 months	Health
Guerra 2011	Peru	Mental	Dementia	Older people	58	6 months	Health
Shin 2009	Vietnam	Mental	Intellectual impairment	Children	37	12 months	Education
Non-randomised stu	ıdies		•				
Ozdemir 2001	Turkey	Physical	Stroke	Adults	60	64 days	Health
Habibzadeh 2007	Iran	Physical	Stroke	Adults	60	45 days	Health
Darmawan 1992	Indonesia	Physical	Arthritis	Adults	844	6 months	Health
Zhang 1998	China	Mental	Schizophrenia	Adults	409	36 months	Health
Chatterjee 2003	India	Mental	Schizophrenia	Adults	207	12 months	Health

#### Table 1: Description of the studies included in the systematic review

Note: COPD refers to chronic obstructive pulmonary disease

## 5. Impact

The following section summarises the key results of the review for each of the components of the CBR matrix, using the causal chain as a structure (Figure 3). The interested reader can refer to the full technical report for the full results of the studies (lemmi *et al.* 2015).

Fifteen studies were identified as eligible for inclusion in the review. These studies were published between 1992 and 2010, and ranged in size from 37 to 844 participants (Table 1). Ten of the studies included were randomised controlled trials (RCTs), meaning that participants were randomised to be in an intervention or control group and the outcomes were compared between these groups. The remaining five studies evaluated people before and after CBR programmes in comparison to people who were not supported with CBR programmes. Follow-up ranged from two months to three years. There was wide variation in the outcomes assessed and how these were measured.

## 5.1. Health component of the CBR matrix

Fourteen of the studies focused primarily on testing interventions for the health component of the CBR matrix.

#### Physical disabilities

Four studies focused on people after stroke. A study in Thailand compared the impact of home healthcare and rehabilitation to usual care (Chinchai *et al.* 2010). The intervention was an educational programme provided for the carers, including lectures given by occupational therapists and weekly home visits. After two months of follow-up, the stroke survivors in the intervention group reported 9–16% higher mean quality of life scores compared to the control group.

A study in Shanghai in China compared the effectiveness of five months of additional home-based rehabilitation versus no intervention (Yu *et al.* 2009). The intervention included 10 training sessions by a general practitioner of the family or carers at home in simple rehabilitation techniques. The stroke survivor was instructed to do functional exercises for 45 minutes at least three times per week, helped by the carer. They were also phoned by the therapists in order to receive help with functional exercises. At five months, the stroke patients in the control group showed 25–36% worse clinical outcomes, measured by neurological function, compared to the intervention group. The differences were not always statistically significant.

The third study was conducted in Edirne, Turkey (Ozdemir *et al.* 2001). The authors compared home-based rehabilitation to acute inpatient hospital-based rehabilitation. The home-based group were shown convenient bed positioning and exercises to be performed

by the stroke survivor and/or carer for two hours per day. Orthotics and devices were provided. A team consisting of a rehabilitation clinician and a physiotherapist visited for two hours weekly. Medical care was also provided if necessary. The inpatients performed therapeutic and neuromuscular exercises and received occupational therapy, which were evaluated daily by medical staff. The results showed that after two months, family-based rehabilitation was less effective than acute rehabilitation in hospital, in terms of motor, functional and cognitive outcomes. The improvement in scores was generally two to six times greater in the hospital-based rehabilitation.

The final study on stroke was undertaken in Iran (Habibzadeh *et al.* 2007). The intervention comprised six to eight educational sessions on self-care delivered at home. Forty-five days after the programme finished, the average score for 'activities of daily living' (ADL) was almost twice as high in the CBR group compared to the control group.

One study assessed the impact of CBR for people with chronic obstructive pulmonary disease (COPD) in Thasala District, Nakhon Si Thammarat Province of Thailand (Noonill *et al.* 2007). The intervention group received community-based group education, individualised home-based care and skill training, enhanced psychosocial support and family supervision. They were compared to a control group which received usual care. At the end of the three-month programme the people supported with CBR had better health status (better exercise tolerance and lower dyspnoea) and better quality of life and satisfaction with care than the control group. Across all the scores, differences were between 20% and 70%. There was no difference in hospital utilisation between the two groups.

Another study in Java, Indonesia (Darmawan et al., 1992) measured the effectiveness of a community educational programme on arthritis that provided simple instructions for coping with neck and back pain, and stiff, swollen or painful joints using traditional puppet shadow play, Wayang. At the six-months follow-up, there was improved knowledge on activities of daily living among the intervention group by 7.9 per cent, while it fell by 1.7 per cent in the control group.

#### Mental disabilities

Five studies focused on people with schizophrenia as the target group. One study evaluated the effectiveness of assertive community treatment tailored for individuals with schizophrenia in Cape Town, South Africa (Botha *et al.* 2010). Each member of the intervention group was assigned a key worker who worked with the person with schizophrenia and a carer, focusing on engagement and adherence to treatment. Participants were frequently referred to occupational therapy and psychology services. Participants from the control group were discharged into the existing community mental health service. After 12 months, the effects of CBR appeared positive, as the scores were higher in the intervention group for clinical status (16–55% higher) and social functioning (13% higher). Psychiatric admissions were almost three-fold higher in the control group. There were no differences in quality of life measures between the two groups.

Another study evaluated the effectiveness of a CBR programme for people with schizophrenia in Chengdu, China (Ran *et al.* 2003). The intervention included family education, family workshops, crisis intervention (if needed) and health education via local village radio. The intervention was delivered by psychiatrists and village doctors. After nine months, people in the intervention group were 85 per cent more likely to be fully recovered compared to those in the control group [risk ratio = 1.85, 95% confidence interval (CI) = 1.22-2.82]. The relapse rate was almost four-fold higher in the control group (61.5%) than the intervention group (16.3%), and treatment compliance was more than six-fold higher for the intervention group. The authors also reported a favourable change in relatives' beliefs on illness.

A study in Jiangsu in China compared a family intervention (group counselling at hospital) with standard care (Zhang *et al.* 1994). For both groups, medication was obtained at the outpatient department. In addition, for the intervention group counselling was provided to family members (e.g. discussing medication adherence and coping strategies). Individual counselling was offered to those with unique or complex problems. After 18 months, the family intervention group were twice as likely to be treatment compliant and three times less likely to be readmitted to hospital. The intervention group also had fewer clinical symptoms and better levels of functioning.

Another study in Jinan and Shanghai in China compared an education programme given to families of people with schizophrenia in addition to the routine community mental health service versus the routine service only (Zhang *et al.* 1998). The intervention included 16 lectures delivered at the health centre by trained psychiatrists/nurses plus seven group discussions. At follow-up after three years, there was no difference in the mean disability score between the intervention and the control arm. The intervention participants had a lower rate of relapse (10.4% versus 15.2%) and hospitalisation (6.4% versus 10.2%), although these differences were not statistically significant.

The fifth study evaluated the effectiveness of CBR for people with schizophrenia in the district of Barwani in the state of Madhya Pradesh, India (Chatterjee *et al*, 2003). The intervention was CBR delivered through outpatient care and community health workers. In addition, family members and key people in the community formed local village health groups, which helped plan rehabilitation measures and reduce social exclusion. At 12 months, people supported with CBR had slightly better (7–13%) clinical status than people receiving standard outpatient treatment.

Three studies assessed the 'Helping Carers to Care' intervention for people with dementia. These were undertaken in three settings: Goa in India (Dias *et al.* 2008),

Moscow in Russia (Gavrilova et al. 2009) and Lima in Peru (Guerra et al. 2011). They aimed to assess the impact of supporting carers in improving outcomes for the person with a disability and the carer. The main focus of the intervention was the carers, and the intervention aimed to increase the carers' knowledge of dementia, provide emotional support to carers and improve their skills (e.g. in managing problem behaviour). The intervention was delivered by a community team. The intervention was compared to a control arm who only received education and information on dementia. Few significant differences were observed after six months of follow-up, in part because the studies were small. Due to consistency in the methods used, it was possible to pool the results from these studies using statistical meta-analysis (Appendix Tables 1 and 2). These pooled analyses show that, on average, the intervention had a significant impact on improving carers' clinical status and quality of life (Table B2). They also suggested the intervention did not improve other outcomes, such as clinical status and quality of life of people with disabilities, and the carers' burden, distress, psychological quality of life or environmental quality of life. However, the available evidence, which covers a small number of studies and participants, is not conclusive.

#### 5.2. Education component of the CBR matrix

Only one study had the education component of the CBR matrix as its primary focus. This study was conducted in Vietnam, focusing on children with intellectual impairment (Shin *et al.* 2009). In the intervention arm, specially trained teachers held weekly sessions of one hour with the parents to train them to work with their children. In the sessions, they reviewed a homework assignment, reviewed the new teaching objectives and demonstrated these objectives. After 12 months, there were no differences in outcomes between the intervention and control groups.

#### 5.3. Livelihood component of the CBR matrix

None of the studies tested interventions primarily focused on the livelihood component of the CBR matrix, but two studies included this component as secondary outcomes.

A study in India compared vocational rehabilitation delivered through outpatient care and community health workers to the usual care for people with schizophrenia (Chatterjee *et al.* 2003). The activity score for occupation increased by 45 per cent more for people in the intervention arm than for those in the controls, but the difference was not significant. A second study in China compared a psychosocial education programme given to families of people with schizophrenia, in addition to the routine community mental health service, to the routine service (Zhang *et al.* 1998). After three years, the intervention participants had a higher rate of regular work (37.5% versus 30.0%).

### 5.4. Social component of the CBR matrix

None of the studies tested interventions primarily focused on the social component of the CBR matrix.

The 'Helping Carers to Care' intervention included provision of emotional support to the families of people with dementia in India, Russia and Peru (Dias *et al.* 2008; Gavrilova *et al.* 2009; Guerra *et al.* 2011). In each setting there was no significant favourable impact of the intervention on the carer, including in mental health or in the perceived burden. A study was undertaken in Thailand among stroke survivors (Chinchai *et al.* 2010). Carers were encouraged to help the stroke survivors to join community activities. After two months the intervention group reported significantly improved quality of life scores, while no change was apparent among the stroke survivors in the control group. A study among people with schizophrenia in India included a focus on improving social networks and access to social benefits (Chatterjee *et al.* 2003). The social and behavioural component of the 'Disability Assessment Schedule' did not show a difference in outcomes between people in the intervention or control groups.

## 5.5. Empowerment component of the CBR matrix

We were not able to locate any controlled studies that assessed interventions related to the empowerment component of the CBR matrix.

## 6. Implications

## 6.1. Implications for policy and practice

The evidence on the effectiveness of CBR in low- and middle-income countries suggests that CBR can be effective in improving the lives of people with disabilities and their carers. A broad range of outcomes were covered, including clinical, quality of life and activity or participation measures, and CBR was observed to be effective across this range. This therefore provides evidence for an impact of CBR at different points in the causal chain: both short- and long-term.

However, the heterogeneity of the interventions and scarcity of good-quality evidence means that we should interpret these findings with caution. It is therefore difficult at this point to outline clear implications for policy and practice as further evidence is required. Importantly, no evidence on cost-effectiveness was reported within any of the studies included, which limits our ability to make clear recommendations. The challenge will be to ensure that research and evaluation becomes a core part of programme implementation.

### 6.2. Implications for research

The studies suggested a modest beneficial effect of CBR interventions in the lives of people with disabilities and their carers. However, there were few studies overall, and the quality of the studies was mixed.

More studies are needed on the effectiveness of CBR in order to build stronger evidence for impact. These new studies should be designed to target the specific gaps in existing studies highlighted in the review:

- 1. Studies conducted need to be of *higher quality*, including a larger sample size and more frequent use of a randomised controlled trial design.
- 2. Studies should *evaluate the entirety of the CBR matrix*, rather than focusing primarily on the health component, to capture the full impact of CBR.
- 3. Studies need to comprise a *broader user group*, beyond those with specific types of physical and mental disabilities, to reflect the usual implementation of CBR.
- 4. The impact of CBR needs to be explored for *children* with disabilities. Only one study focused on children as the target for CBR (Shin *et al.* 2009).
- 5. More studies are needed to evaluate the effectiveness of CBR within *Africa*. Only one study was included from sub-Saharan Africa (Botha *et al.* 2010), despite the fact that a variety of CBR programmes have been implemented in Africa.
- 6. *Economic evaluation* is needed to supplement and strengthen the evidence on effectiveness.

Strengthening the evidence base for CBR through conducting better studies will therefore allow clearer recommendations to be made for policy and practice so that the implementation of CBR can be scaled-up more rapidly and effectively.

## Appendix A: CBR guidelines outcomes

#### 1 Health

- 1.1 People with disabilities and their families are reached by the same health promotion messages as are members of the general community.
- 1.2 Health promotion materials and programmes are designed or adapted to meet the specific needs of people with disabilities and their families.
- 1.3 People with disabilities and their families have the knowledge, skills and support to assist them in achieving good levels of health.
- 1.4 Healthcare personnel have improved awareness about the general and specific health needs of people with disabilities and respond to these through relevant health promotion actions.
- 1.5 The community provides a supportive environment for people with disabilities to participate in activities which promote their health.
- 1.6 CBR programmes value good health and undertake health-promoting activities in the workplace for their staff.

#### 2 Education

- 2.1 All persons with disabilities have access to learning and resources that meet their needs and respect their rights.
- 2.2 Local schools take in all children, including children with disabilities, so they can learn and play alongside their peers.
- 2.3 Local schools are accessible and welcoming; they have a flexible curriculum, teachers who are trained and supported, good links with families and the community, and adequate water and sanitation facilities.
- 2.4 People with disabilities are involved in education as role-models, decision makers and contributors.
- 2.5 Home environments encourage and support learning.
- 2.6 Communities are aware that people with disabilities can learn, and provide support and encouragement.
- 2.7 There is good collaboration between the health, education, social and other sectors.
- 2.8 There is systematic advocacy at all levels to make national policies comprehensive to facilitate inclusive education.

## 3 Livelihood

- 3.1 People with disabilities have access to skills development and lifelong learning opportunities.
- 3.2 Parents of children with disabilities advocate for access to education, skills acquisition and work opportunities for their children.
- 3.3 People with disabilities have access to decent work opportunities without discrimination in a safe and non-exploitative environment.
- 3.4 People with disabilities have access to microfinance services.
- 3.5 Women with disabilities have equal opportunities for work and employment as men.
- 3.6 Families of people with disabilities, especially children and people with severe disabilities, have access to better means of livelihood.
- 3.7 All poverty reduction strategies and programmes include and benefit people with disabilities and their families.
- 3.8 The work of people with disabilities is recognised and valued by employers and community members.
- 3.9 Local authorities adopt and apply policies and measures to improve the access to work for people with disabilities.
- 3.10 People with disabilities have access to social protection measures as a right.

## 4 Social

- 4.1 People with disabilities have the same access to social security measures against loss of income through old age, sickness or disability as other citizens.
- 4.2 People with disabilities who are out of work, earn too little for a decent living or are unable to work, have access to available social protection measures.
- 4.3 Existing social services providers are sensitised and aware of the specific difficulties faced by people with disabilities and adapt their service provision accordingly.
- 4.4 Social security providers develop partnerships with people with disabilities, through their representative organisations and service providers, to adapt practices to their specific needs.

## 5 Empowerment

- 5.1 People with disabilities and their families have improved access to information and communication resources.
- 5.2 Communication barriers for people with disabilities are reduced and/or eliminated.
- 5.3 People with disabilities and their families represent themselves in their respective communities.
- 5.4 CBR personnel are effective communicators and share information with all stakeholders including those who have communication difficulties.

## **Appendix B: Meta-analysis results**

Outcome	Measure	Studies	Participants	Average change in outcome between treated and non- treated (SMD) [95% CI]
Clinical status at 6 months	Neuro-psychiatric inventory (NPIQ-D)	3	168	-0.09 [-0.47, 0.28]
Quality of life at 6 months	Dementia-specific health-related quality of life (DEMQOL)	2	109	0.22 [-0.33, 0.77]

Table B 1: Meta-analysis results for dementia (users): CBR vs. treatment as usual

Notes: No findings are statistically significant. The change in outcome between groups that received CBR and those that did not is measured by the standardised mean difference (SMD). Average change in outcomes was estimated across studies using random effects statistical meta-analysis.

Outcome	Measure	Studies	Participant s	Average change in outcome between treated and non- treated (SMD) [95% CI]
Carer burden at 6 months	Zarit burden scale (ZBS)	3	168	-0.85 [-1.24, -0.45]****
Carer distress at 6 months	Neuro-psychiatric Inventory (NPIQ-D)	3	168	-0.16 [-0.54, 0.22]
Carer psychological morbidity at 6 months	Self-reporting questionnaire 20 (SRQ- 20)	2	109	-0.37 [-1.06, 0.32]
Carer physical quality of life at 6 months	WHO quality of life questionnaire (WHOQOL-BREF, physical)	2	88	0.51 [0.09, 0.94]*
Carer psychological quality of life at 6 months	WHO quality of life questionnaire (WHOQOL-BREF, psychological)	2	88	0.11 [-0.31, 0.53]
Carer social quality of life at 6 months	WHO quality of life questionnaire (WHOQOL-BREF, social)	2	88	0.54 [0.12, 0.97]**
Carer environmental quality of life at 6 months	WHO quality of life questionnaire (WHOQOL-BREF, environment)	2	88	0.07 [-0.35, 0.49]

Table B 2: Meta-ana	lysis results for dementia (	(carers): CBR vs. treatment as usual
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Notes: \* indicates finding is statistically significant at  $P \le 0.05$ . \*\* indicates finding is statistically significant at  $P \le 0.01$ . \*\*\*\* indicates finding is statistically significant at  $P \le 0.0001$ . The change in outcome between groups that received CBR and those that did not is measured by the standardised mean difference (SMD). Average change in outcomes was estimated across studies using random effects statistical meta-analysis.

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Community-based rehabilitation (CBR) is a strategy for the rehabilitation, poverty reduction, equalisation of opportunities and social inclusion of all people living with disabilities, which is endorsed by the World Health Organization. This report is based on a systematic review that looked at the impact of CBR on health, education, livelihoods, social inclusion and empowerment. Most of the studies in the review found CBR to be an effective strategy. CBR also improved the clinical outcomes for people living with disabilities, reduced the burden on care givers and improved overall quality of life. Most of the limited evidence currently available is focussed on adults and the elderly living in Asia. Although CBR is intended as a strategy for people with all types of disabilities, the studies mostly focused on a few physical and mental health conditions and did not include sensory impairments.

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