

Community based rehabilitation (CBR)

Q4: Should community based rehabilitation be offered to children with intellectual disabilities?

Background

Concern with the coverage, cost and equity of access to institution-based rehabilitation services in low and middle income (LAMI) countries has led to the development and promotion of community-based alternatives. Specifically, community-based rehabilitation (CBR) was developed in the 1980s, 'to give people with disabilities access to rehabilitation in their own communities using predominantly local resources'¹.

Following a major review of CBR (World Health Organization 2003), it has recently been reconceptualised as a strategy for (re)habilitation, equalization of opportunity, poverty reduction and the social inclusion of people with disabilities (International Labour Office, United Nations Educational Scientific and Cultural Organization, & World Health Organization 2004).

At present it is claimed that CBR is being implemented in more than 90 countries in order to 'promote collaboration among community leaders, people with disabilities, their families, and other concerned citizens to provide equal opportunities for all people with disabilities in the community'.^a

There have, however, been repeated concerns voiced about the adequacy of the evidence-base regarding the efficacy, effectiveness and efficiency of CBR (Finkenflugel et al, 2005; Kuipers et al, 2008; Mannan & Turnbull 2007; Mitchell 1999; Sharma 2007; Wirz & Thomas 2002).

Population/Intervention(s)/Comparator/Outcome(s) (PICO)

Population: children with intellectual disabilities

Intervention(s): community-based rehabilitation

Comparator(s): care as usual

Outcome(s): functioning in school

¹ <http://www.who.int/disabilities/cbr/en/>

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family functioning

symptom reduction

reduction of risky behaviour

physical health

user and family satisfaction

adverse effects of treatment (as applicable)

Systematic review commissioned

Robertson J, Emerson E and Hatton C (2009). The efficacy of community-based rehabilitation for children with or at significant risk of intellectual disabilities in low and middle income countries. Lancaster: Centre for Disability Research. (commissioned and received in 2009).

Narrative description of the studies that went into the analysis (including a study-by-study table)

A small number of reviews have looked at studies which evaluate CBR (Finkenflugel et al, 2005; Kuipers et al, 2008; Mannan & Turnbull 2007; Mitchell 1999; Sharma 2007; Wirz & Thomas 2002). These reviews give an indication of the small amount of attention paid to ID in this body of literature. Whilst Mitchell (1999) aims to review the research on CBR, there are no figures given for the number of studies identified for the review or how these were identified. In terms of the types of disabilities covered in the studies, Mitchell (1999) notes that leprosy is the most common, and also mentions those who have acquired disability through head and brain injury, stroke, and people with mental health problems. Research relating to children with ID mentioned in the review was limited to one home-based programme published pre-1990 which looked at children and young adults (Mariga & McConkey 1987) and an anecdotal report by the author of the existence of a programme based in Singapore (Mitchell 1999). A review was published by Wirz & Thomas (2002) which has the specific focus of identifying the indicators used in 10 published evaluations of CBR although ID per se is not mentioned in this review.

The most comprehensive review of literature on evidence for CBR to date is that of Finkenflugel et al (2005) who note that after 25 years of CBR no systematic review is available although some reviews on selected aspects of CBR have been published (as described above). Their review aimed to establish the evidence-base for CBR looking at articles in English published from 1978-2002 relating to LAMI countries (Finkenflugel et al, 2005). They identified a total of 128 articles, comprised of the following: 10 intervention studies; 40 descriptive studies; 14 case reports; 8 review papers; 55 theory papers; 1 “other” paper. In relation to

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the intervention studies, results were noted to be almost completely based on questionnaires and interviews with little use of developmental tests or standardized assessment of functional skills. They note that whilst studies have attempted to compile sets of indicators to judge the effectiveness of CBR (Wirz & Thomas, 2002), they did not identify any studies using these sets of indicators (Finkenflugel et al, 2005). Whilst Finkenflugel et al (2005) note a steady increase in articles about CBR over time, they suggest that the only aspect covered satisfactorily at that time was “screening”.

A more recent article by Sharma (2007) aims to qualitatively analyse the extent to which the CBR approach and programmes have been evaluated over the preceding 30 years (Sharma 2007). Searches were conducted in MEDLINE to identify articles in English published since 1980 which described any aspect of either a qualitative or quantitative evaluation of a CBR programme. A total of 22 articles were included in the review but the review was not restricted to LAMI countries and only 14 of the articles were from LAMI countries. Sharma (2007) notes that as CBR operates in resource-poor settings, it is often difficult to find resources for conducting evaluations and that conscious efforts need to be made in the planning stage to budget for programme evaluation, echoing the comments of Mitchell (1999). Sharma (2007) notes that one weakness of the evaluation research conducted is that other than mobility disabilities, other disabilities have not been adequately addressed. Other weaknesses of CBR evaluations were noted to be: lack of consistency in outcome measures; lack of information on cost-effectiveness; and small sample sizes.

The review by Mannan & Turnbull (2007) reviews articles involving an evaluation of CBR in specifically in LAMI countries. The review is based on 30 journal articles published in English from 1987 to 2002 although there is no information given on the search strategy employed. Of the studies reviewed, only two were impact evaluations and the rest process evaluations. They note that a complete review of CBR evaluations is difficult because most of them remain unpublished and little quality research on CBR has been published. They argue that future CBR evaluations should provide empirical evidence on whether or not it enhances quality of life and propose a tool that measures family quality of life as an outcome measure for future evaluations (Mannan & Turnbull 2007).

Finally, in a recent article Kuipers et al (2008) point to the WHO consultation on CBR (World Health Organization 2003) which says that Governments want evidence based practices, so CBR programmes must be ready to provide evidence and that researchers and NGOs should work on evaluation and research on evidence based practices in order to contribute to planning, policy making and to assist with decision making for the scaling-up of CBR globally. Kuipers et al (2008) note that: “Unfortunately, with the exception of a recent detailed review (Finkenflugel et al, 2005) and some specific reviews (Mitchell 1999), there are few studies in CBR which might be used to contribute to such an evidence base within traditional approaches to determining evidence” (p2). To address this lack of evidence, Kuipers et al (2008) propose a method for the qualitative synthesis of CBR evaluation reports and assesses the suitability of conducting qualitative thematic analysis using the recommendations section of reports (Kuipers et al, 2008). They included a total of 37 reports in English from “Source”² and the authors’ own personal libraries which evaluated CBR for people with disabilities in 22 LAMI countries covering the years 1996-2006. The finding for the

² Source: International information support centre. <http://www.asksource.info/index.htm>

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minor node (a theme mentioned by more than 25% but less than 50% of evaluation reports) “Target disability type” was that a key issue for specialised focus in CBR is to assist people with ID (p11). This is the only mention of ID within this review.

In summary, these reviews of CBR evaluations suggest that evidence for the effectiveness of CBR per se is lacking and little focus has been directed at ID. As concluded by Finkenflugel et al (2005): “The evidence base for CBR is, despite 25 years of experience with the concept and a growing amount of literature on the topic, still fragmented and therefore its effectiveness cannot be sufficiently established” (p197). As this conclusion relates to CBR generally, it seems unlikely that there will be sufficient evidence to establish the effectiveness of CBR for children and adolescents with ID as a specific group.

*LIC: low income country; LMIC: lower middle income country; UMIC: upper middle income country

Study	Country	World Bank Classification	Setting	Sample Size	Design/purpose	Outcome Measures	Results	Other Comments
Arya S (2002).	India	LMIC	2 rural areas of India	63 villages; 119 children age 0-12 with ID; 11 itinerant teachers	Pre-/post test evaluation of itinerant service model	Vineland Social Maturity Scales (Social Quotient - SQ)	Pooled results for SQ 41.8 pre & 51.7 post intervention (t-test $p < .01$). SQ significantly higher for both 0-6 & 6-12 year olds and for girls and boys	Anecdotally report that there was a positive change in parents' attitudes to their child with ID

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Study	Country	World Bank Classification	Setting	Sample Size	Design/purpose	Outcome Measures	Results	Other Comments
Hamblin T, Musa I (2006)	India	LMIC	3 urban slums, Kolkata	20 children with cerebral palsy (not possible to ascertain whether any children also had ID)	Action research introducing family based rehabilitation; qualitative comments	Goals met by children as part of goal-oriented intervention	All of the children showed an improvement with the majority of the goals being met. Parents and fieldworkers all reported positive experiences of involvement in the programme.	There is no mention of ID and the research focuses on aspects of physical disability. Although most parents had to work long hours, close family ties meant that there was usually someone else willing to carry out the tasks such as grandmothers or aunts.

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Study	Country	World Bank Classification	Setting	Sample Size	Design/purpose	Outcome Measures	Results	Other Comments
Lagerkvist B (1992).	Phillipines & Zimbabwe	LMIC & LIC	CBR programmes in Phillipines & Zimbabwe	206 people with disabilities aged 5-70 years of whom 34 with ID aged 6 to 20 years	Pre-/post test evaluation of ability	Ability score in areas such as dressing, eating, talking but pre- CBR measure collected retrospectively from verbal reports & records	Increase in ability score was found for each type of disability and overall, 78% of those in the Phillipines and 93% of those in Zimbabwe did show some improvement	Ability score increased for group of 34 participants with learning difficulties aged 6 to 20 years but pre-CBR assessment of ability flawed

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Study	Country	World Bank Classification	Setting	Sample Size	Design/purpose	Outcome Measures	Results	Other Comments
McConachie H et al (2000).	Bangladesh	LIC	Urban & rural settings in Bangladesh	85 children with cerebral palsy randomized; 58 followed up	RCT of distance training, centre based program, & minimal advice groups	Child ability using Independent Behaviour Assessment Scale (IBAS); maternal stress, Maternal Adaptation to the Child (Judson Scale), the Family Support Scale, and a 10-item questionnaire on parental knowledge of information related to training manuals.	For rural children, minimal intervention group mean IBAS z scores compared with the norm dropped significantly (t=2.78, p<.02). In the distance training package, there was a small but non-significant drop in z score. The degree of change was not statistically different between the two groups. Mother's perception of the helpfulness of formal sources of support increased in the distance training group significantly compared to the minimal intervention group (t=2.77, p<.02). Differential change was not found for 3 of the 4 maternal variables. For urban children, z scores did not decline significantly for either centre based or outreach groups. Maternal adaptation to the child increased significantly in the centre based group. There was a non-significant increase in maternal stress in both groups.	Outreach group involved the need to visit a distant centre so not CBR per se. Authors note the need for family support reinforced through home visits. Some children may have had ID but no specific mention of this.

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Study	Country	World Bank Classification	Setting	Sample Size	Design/purpose	Outcome Measures	Results	Other Comments
Menon D et al (1993).	India	LMIC	4 urban slums in India	90 children with ID identified; 4 community workers trained as teachers of ID; 9 parents attended training	Pre-/post test evaluation of CBR	Unclear. No standardized outcome measures.	Presented as tables and charts. No statistics are presented. CWs trained as teachers in 3 months. Community understanding of ID increased.	Not a peer reviewed article. Reports given by community workers indicate that parents rarely carry out instructions given to train children with ID in the home setting
Narayan J, Reddy PS (2008).	India	LMIC	Existing CBR programme in Andhra Pradesh	25 middle level functionaries	Pre-/post test evaluation of training of trainers programme; anecdotal evidence on impact	Multiple choice questionnaire on knowledge of ID	Scores on questionnaire increased from mean 70% to mean 85%; anecdotal reports of progress by people with ID but not clear if this includes children	Authors note that most CBR programmes focus on aids, appliances, physiotherapy and so on with minimum focus on ID
Nordholm LA, Lundgren-Lindquist B (1999).	Botswana	UMIC	Village in Botswana	132 people with disabilities; 22% <15 yrs old; 33% ID	Follow up of CBR participants	n/a	Not possible to extract data with regards to children/adolescents with ID per se	No mention of the effectiveness for children with ID

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Study	Country	World Bank Classification	Setting	Sample Size	Design/purpose	Outcome Measures	Results	Other Comments
Sen R, Goldbart J (2005).	India	LMIC	Urban slums	22 children % young adults with disabilities including 7 children with ID	Action research introducing family based intervention; qualitative comments	n/a	Some positive changes for participants noted; positive changes in family attitude noted	Conclude that CBR is a feasible approach to provision of disability related services in resource-poor environments
Shin JY et al (2009).	Vietnam	LIC	Home based intervention in large city in Vietnam	30 children with ID aged 3-6 years; 11 teachers with experience of ID	RCT of 1 year intervention with testing at 0, 6 & 12 months	VABS	Intervention group gained more than the control group in the VABS areas of motor skills (F=3.9, p<.05) and daily living skills (F=2.7, p<.05) over one year	The programme was not suitable for all children with ID & involved considerable input by teachers with experience of ID

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Thorburn MJ (1992).	Jamaica	UMIC	CBR programme in Jamaica	375 parents	Parental evaluation of CBR via questionnaire	Parental report	76% of parents said that their child had done better since being in the programme	Questionnaires were anonymous so it is not possible to look at responses based on different categories of disability

Summary analyses

Only 10 studies were identified for inclusion in the review of research on the effectiveness of CBR for children and adolescents with ID and these are summarised in Appendix Two. An examination of reviews on the effectiveness of CBR for all people with disabilities points to two main reasons for this low level of evidence. Firstly, CBR has not been the subject of a significant amount of rigorous evaluation. Secondly, children and adolescents with ID have not been the recipients of significant amounts of CBR. We will discuss the reviews on the effectiveness of CBR generally and indicate what they say about ID before outlining the extremely small amount of information available on the effectiveness of CBR for children and adolescents with ID.

The systematic review by Maulic & Dormstadt 2007 also highlights lack of evidence on effectiveness of CBR in low and middle income countries and the need for more research.

Methodological limitations

Small number of studies. Our general review of the literature indicates that children (or adults) with intellectual disability are rarely mentioned within the existing evaluation literature. Methodologically, there have been repeated concerns voiced about the adequacy of the evidence-base regarding the efficacy, effectiveness and efficiency of CBR per se (Finkenflugel et al, 2005; Kuipers et al, 2008; Mannan & Turnbull 2007; Mitchell 1999; Sharma 2007; Wirz & Thomas 2002).

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Directness (in terms of population, outcome, intervention and comparator)

There are some studies from low income countries but few address ID in particular. So directness can be considered as moderate.

Any additional information (safety and tolerability issues, cost, resource use, other feasibility issues, as appropriate)

There is no perceived harm from community based initiatives and there is considerable international experience that it is feasible.

Narrative conclusion

Evidence is very low for all outcomes. There is however no evidence that CBR is ineffective for intellectual disabilities. CBR seems to be a feasible approach to providing disability services in resource-poor environments and there is no reason to exclude intellectual disabilities in CBR programmes.

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From evidence to recommendations

Factor	Explanation
Narrative summary of the evidence base	The evidence is inconclusive and so it is not possible to determine if CBR is effective in intellectual disabilities for specified outcomes.
Summary of the quality of evidence	Very low
Balance of benefits versus harms	There is no perceived harm and some positive changes have been reported.
Values and preferences including any variability and human rights issues[†]	The convention on the rights of people with disabilities emphasizes to include people with intellectual disabilities. Community based interventions are more in line with the rights of people with disabilities as it provides opportunities for them to participate and be considered as equal members of the society.
Costs and resource use and any other relevant feasibility issues	CBR seems to be cost saving and feasible. However more work is needed to show how best we can include ID within the programmes.
Recommendation(s) Non-specialized health care providers should consider supporting, collaborating and facilitating referral to and from community based rehabilitation (CBR) programmes, if available, for care of persons with intellectual disabilities. Strength of recommendation: STANDARD	

Update of the literature search – June 2012

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In June 2012 the literature search for this scoping question was updated. The following systematic review was found to be relevant without changing the recommendation:

[Robertson J](#), [Emerson E](#), [Hatton C](#), [Yasamy MT](#). Efficacy of community-based rehabilitation for children with or at significant risk of intellectual disabilities in low- and middle-income countries: a review. [J Appl Res Intellect Disabil](#). 2012 Mar;25(2):143-54. doi: 10.1111/j.1468-3148.2011.00679.x.