



Centre for Disability Research

The Efficacy of Community-Based
Rehabilitation for Children with or at
Significant Risk of Intellectual Disabilities in
Low and Middle Income Countries:
A Review

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Introduction

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'^a. To this end the WHO have produced training manuals for practitioners (World Health Organization, 1989), guidelines for monitoring and self-assessment (World Health Organization & International Disability Consortium, 1996), sponsored evaluations of CBR (World Health Organization & Swedish Organizations of Disabled Persons International Aid Association, 2002a, 2002b) and is currently establishing a global database of CBR practice^b.

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).

Within this framework, the major objectives of CBR are:

1. 'To ensure that people with disabilities are able to maximise their physical and mental abilities, to access regular services and opportunities, and to become active contributors to the community and society at large.
2. To activate communities to promote and protect the human rights of people with disabilities through changes within the community, for example, by removing barriers to participation' (International Labour Office et al., 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, Wolffers, & Huijsman, 2005; Kuipers, Wirz, & Hartley, 2008; Mannan & Turnbull, 2007; Mitchell, 1999; Sharma, 2007; Wirz & Thomas, 2002). The results of these reviews are discussed below.

The aim of the present review is to summarise evidence regarding the efficacy of CBR in relation to one particular 'high risk' group of disabled children; children with intellectual disabilities.

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

^b http://www.who.int/disabilities/cbr/global_database_form/en/index.html

Method

Searches of electronic literature databases were conducted in June 2009 to identify peer reviewed articles published from 1990 onwards in the English language, which included information from relevant studies in low and middle income (LAMI) countries. Eligibility for inclusion of countries was determined by reference to the World Bank List of Economies^c. In this, economies are divided among income groups according to 2007 gross national income (GNI) per capita, calculated using the World Bank Atlas method. The groups are: low income, \$935 or less; lower middle income, \$936–3,705; upper middle income, \$3,706–11,455; and high income, \$11,456 or more.

The databases searched were:

- Medline
- Cinahl
- Web of Science
- PsycINFO

In each database, terms for intellectual disabilities and associated synonyms were identified. The most appropriate method for searching for research from LAMI countries was also identified. These two searches were then combined to get a pool of literature dealing with ID and LAMI countries. Within this pool specific search terms relating to the review in hand were then introduced (e.g. screening; identification). Full details of the search strategies and terms employed can be found in Appendix One. All articles identified by searches were assessed for their relevance to the review objectives firstly by reading abstracts. If abstracts were unavailable, or did not provide enough detail to assess the relevance of the article, the full text of the article was obtained and relevance assessed from this. Data was extracted from the full text of articles identified as being relevant to the review.

In addition, a request for information on research relevant to all three rapid reviews carried out in this series was sent by email in April 2009 to the membership of the International Association for the Scientific Study of Intellectual Disabilities (IASSID). This enabled the identification of research literature not identified in the electronic searches, for example relevant articles which were “in press”.

A request for information was also sent to relevant organisations in LAMI countries targeted in the WHO Mental Health Gap Action Programme (mhGAP). These countries are those highlighted in bold in Appendix Two of the mhGAP document (World Health Organization, 2008). Informants were asked for information on current policy and practice in their country; descriptions of relevant services in their country; and reports that have evaluated the impact of relevant services in their country. Relevant contacts in each targeted country were identified from the Atlas-ID Compendium of Sources Used (Gabrielle Major, Lisette Dupras, & West Montreal

^c siteresources.worldbank.org/DATASTATISTICS/Resources/CLASS.XLS

Readaptation Centre, 2008). Initially, emails were sent to contacts but in instances where messages were returned as email addresses no longer existed, letters were sent by surface mail to the address listed in the Atlas-ID Compendium. Contacts were invited to reply either by email or by surface mail.

Results

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.

Reviews of the Effectiveness of CBR

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. The earliest of these was published in 1999 (Mitchell, 1999). 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 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). Mitchell suggests that the context within which CBR has been developed explains in part the lack of research and evaluation surrounding its' implementation (Mitchell, 1999). With need being so obvious and pressing, and both financial and manpower resources being limited, committing resources to research and evaluation of CBR programmes has not been a priority (Mitchell, 1999).

A few years later a review was published by Wirz & Thomas (2002) which has the specific focus of identifying the indicators used in 10 published evaluations of CBR. The method for identifying these 10 evaluations is not specified but it is noted that they used the following criteria for inclusion: evaluation published or widely circulated; independent evaluation; conducted in the preceding 10 years; and published in English. They note that: "It is the view of the current authors that much that passes as evaluation of CBR is description of activity and an encouraging pat on the back for a programme" (p166). That is, they suggest that evaluations tend to describe practice rather than the effectiveness of that practice. One problem they point to is the use of diverse evaluation methods that makes any meta-analysis of published evaluations impossible. They argue the need for indicators that can be used in evaluations of CBR in order that CBR programmes can be shown to have demonstrable achievements so that policy makers can justify the use of such programmes (Wirz & Thomas, 2002). 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, Wolffers & Huijsman (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, although it should be noted that their electronic literature searches did not include *The Asia Pacific Disability Rehabilitation Journal* which, in literature searches for the review in hand, was found to feature highly as a source of articles on CBR in LAMI countries. The 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 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 and 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 measures for future evaluations (Mannan & Turnbull, 2007).

Finally, in a recent article Kuipers & Hartley (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 & Hartley (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 & Hartley (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”^d 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 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.

CBR and ID: The Example of Pakistan

This lack of evidence is reflected in several articles regarding the situation in Pakistan which note the lack of effective CBR interventions for people with ID (Jaffer & Jaffer, 1994; Miles, 1993; Mirza, Tareen, Davidson, & Rahman, 2009). Mirza et al (2009) report a lack of effective community management of ID in Pakistan. This mixed methods study looked at community management of ID in the Punjab province of Pakistan. The main findings were that:

- detection was delayed due to a lack of an effective system of routine child health checks;
- there was a time lag between identification of developmental concerns and presentation to a healthcare provider;

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

- a fundamental barrier to treatment was the lack of awareness of effective interventions which are likely to improve outcome;
- management at home was mainly physical restraint and strict family supervision;
- there was significant stigma associated with ID resulting in decreased opportunity for these children and families to participate in community activities and high levels of stress in carers;
- there was a lack of recognition and knowledge of basic management of ID at the primary care level.

They conclude that their study supports the need to develop a feasible, cost-effective, community level intervention which can be scaled up and integrated into existing healthcare systems. As this study was done in Punjab, the largest and best-resourced of all four provinces in Pakistan, community management of ID is unlikely to be better in other provinces of Pakistan (Mirza et al., 2009).

The involvement of children with ID in CBR programmes in Pakistan is described in the context of the historical background of community-oriented service development from the 1860s to more recent formal CBR programmes (Miles, 1998). Miles (1998) concludes that ID has had a low priority in CBR projects, noting that: "It was understandable that local associations concentrated initially on physical disabilities. They were more visible, easier to conceptualise, and treatment methods were more easily demonstrated. Mental handicap was and still is poorly understood" (p435). An earlier survey among leaders of Pakistan's ID work by Miles (cited in Miles, 1998) identified staff skills for CBR as one of the most serious shortages. Further, Miles notes that: "Especially with regard to mental handicap, there has been very little research on the effectiveness of CBR or community outreach in Pakistan. The keenness of funding agencies, often far from the scene, to hear of increasing numbers of children "reached," is seldom matched by funding for research that might show whether the reaching brought any real and lasting benefit" (p438).

Miles suggests that briefly trained CBR workers may become depressed by the slowness of progress and decide that a particular child is incapable of learning anything, rather than persevering and using a variety of approaches. Miles concludes that: "Rural families having members with mental handicap receive no more professional help that did their great-grandparents. Urban services have expanded, and over 40 centres are now running, mostly special schools and a few sheltered workshops. Recently, many of the urban centres began projects for outreach or CBR ... These schemes are experimental. Formal reporting with critical evaluation is barely beginning ... Almost everything remains to be discovered, analysed and cross-checked" (p445).

A CBR project in villages and slums in Punjab, Pakistan is described in a pithy account of the CBR approach (Jaffer & Jaffer, 1994). A total of 83 trainees completed the Local Supervisor (LS) course which took 30 hours spread over 2 weeks. They note that programme impact was inversely related to demand on the family, and training a child with ID was noted to be associated with maximal demand and low

effectiveness. Indeed, they suggest that: “Training and education of mentally handicapped persons is an area in which the WHO-CBR programme in Pakistan experienced total failure” (p338).

The Impact of CBR for Children and Adolescents with ID

This review now considers the very small amount of research that does consider the effectiveness of CBR for children with ID. In this section we review studies which look at the effectiveness of CBR, either in relation to children with ID, or studies on the effectiveness of CBR for people with disabilities generally which mention children with ID as being part of the sample. These studies are introduced chronologically.

Lagerkvist 1992: CBR Evaluation in Phillipines & Zimbabwe

A small amount of data can be gleaned from a study that reports the results of two evaluations of CBR undertaken in the Phillipines (106 participants) and Zimbabwe (100 participants) (Lagerkvist, 1992). The sample included both adults and children (over the age of 4 years) with age range of 5 to 70 years. Of the total sample of 206, 34 were classed as having learning difficulties and the age range for this group was 6 to 20 years (mean 13 years in Phillipines, mean 17 years in Zimbabwe). Current ability was assessed based on observed performance of, or verbal descriptions of, activities such as eating, dressing, talking and moving around. Ability was scored and compared with what could be expected of a non-disabled person of the same age. However, ability before the start of the CBR programme was judged from a retrospective verbal history and the individual’s records. An increase in the ability score was used as a measure of the benefit received from the CBR programme. An 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. Hence, an increase in ability score was found for a group of 34 participants with ID aged from 6 to 20 years (this is presented graphically; actual scores are not presented). However, as noted by the author, a flaw in the study is the poor assessment of ability for prior to the CBR programme.

Thorburn 1992: Parent Evaluation of CBR in Jamaica

A CBR programme in Jamaica involving children with all types of disabilities (including ID) was evaluated through a survey of parents’ views of the CBR service (Thorburn, 1992). A total of 375 questionnaires were included in the analysis. However, questionnaires were anonymous so that it was not possible to look at responses based on different disability categories thus it was not possible to draw any conclusions in relation to type or severity of disability, or age. Thus, whilst it was found that 76% of parents said that their child had done better since being in the programme, it is not possible to determine whether this is the case for children with ID per se.

Menon et al 1993: CBR in Urban Slums in India

Menon, Ojha, Jena et al (1993) looked at the feasibility of introducing services for children with ID using the community based approach (Menon, Ojha, Jena, Kumar, & Chander, 1993). The study was carried out in four urban slum areas in India. Efforts

were made to evaluate the efficacy of transfer of skills and competency to the community workers with reference to the assessment and training of children with ID. They also looked at raising awareness in the community for the detection of children with disabilities and empowering parents for home training. They set up a special education centre in each of the 4 areas to provide centre based and home based training to children with ID. Children were identified as having developmental delay using the TQS and subsequent assessment by a clinical team. A total of 203 children with disabilities were identified of whom 90 had MR.

Community workers were trained to determine a baseline to start a training programme to build skills in children with ID and to use an activity based curriculum to train children in motor, cognitive, social, language and personal and self help skills. . They were able to train a community worker as a teacher in the special education centre (one centre in each of the 4 slum areas) which took 3 months. A public awareness campaign used films, posters and small group discussions. Pre and post assessment showed greater awareness of ID. A parent training programme was attended by 9 parents and pre and post training results showed increased knowledge. However, reports given by community workers indicate that parents rarely carried out instructions given to train children with ID in the home setting. They found that it was necessary for a team from an institution to visit the slum areas at regular intervals to make detailed assessments and referrals and also to support the programme at the special education centre. Whilst this article does present some tables and bar charts, this is not a peer reviewed journal and there are no statistics presented for example to compare pre and post intervention scores.

Nordholm & Lundgren-Lindquist 1999: CBR in Botswana

In a CBR programme in a village in Botswana, 151 disabled persons were identified via a house to house survey of whom data was available for 132 (Nordholm & Lundgren-Lindquist, 1999). Rehabilitation interventions were proposed for all those identified and two follow up studies conducted. Of those identified, 22% were younger than 15 years of age and the second largest group was those with ID (33%). However, it is not possible to extract any information with regards to children with ID per se. The only point noted with regards to children is that the CBR programme had promoted integration into normal schools for physically disabled children and referrals to special schools for those with hearing and seeing disabilities. Hence, no information of the effectiveness of CBR for children with ID can be extracted from this study.

McConachie et al 2000: RCT of Service Provision for Children with Cerebral Palsy in Bangladesh

A randomized controlled trial in Bangladesh looked at the efficacy of an outreach program for young children with cerebral palsy compared with control groups who received centre-based (for urban children) or minimal intervention (for rural children). Of 85 children randomized, 58 were available for follow up. All children were assessed by a neurodevelopmental paediatrician as having cerebral palsy.

Whilst it seems likely that some of these children may have had ID, no mention of ID per se is made in the paper.

Distance training packages were used as an outreach method of giving advice to parents which included pictorial manuals illustrating positions, activities and simple home-made aids. They also had manuals to cover motor skills, speech and language, and cognitive skills. However, suggestions appropriate to the child's development were practiced at a clinic with parents before they took the manual home so the intervention is not CBR per se. The centre-based group involved regular attendance at the centre. The minimal intervention involved giving parents health advice and a box of toys and books for the children to play with at home. Changes in adaptive behaviour were assessed using the Independent Behaviour Assessment Scale (IBAS). Maternal measures were Maternal Adaptation to the Child (Judson Scale), the Family Support Scale, and a 10-item questionnaire on parental knowledge of information related to the training manuals.

For the rural children, for the 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.

The authors suggest that they have established evidence of the effectiveness of an outreach program for young children with cerebral palsy based on brief training of mothers who were given pictorial manuals to take home. However, participation increased stress for some mothers which may have been related to the need to return to distant services which were hard to access and may have increased frustration in being unable to help their child consistently. This element of the outreach program was not in line with the principles of CBR and the authors suggest that services should be widened to include support to mothers reinforced through home visits.

Arya 2002: Delivery of Services Through an Itinerant Worker Model

A study in two rural areas of India looked at the impact of an itinerant service model on the social competence of children with ID. Arya notes that services for people with ID are primarily concentrated in urban areas and it is only recently that CBR programmes have been initiated through the District Rehabilitation Centre (DRC) Scheme of the Government of India (Arya, 2002). The vast majority of people with ID in rural areas are unreached. It is suggested that the most promising way of assisting disabled people and their families is CBR. Community based services primarily depend on local area itinerant workers instead of skilled professionals based in urban institutions.

This study aimed to develop and study the effectiveness of a model of comprehensive services for children with ID living in the rural community by establishing a network of services delivered through a village based itinerant worker. The study was conducted in two rural areas in India. In site one, 30 villages were selected and site two 33 villages. A house to house survey identified 60 children with ID in site 1 and 60 in site 2. One child died leaving the total sample size 119. Eleven itinerant teachers were selected for giving training in early detection and management of ID children in rural areas. Training was based on manuals published by NIMH and took one month. Each child was assessed at the beginning of the study by the itinerant teachers using the Vineland Social Maturity Scale. Baseline social age (SA) and social quotient (SQ) was computed for each child.

The intervention programme included: an individualized training programme (ITP); parental counselling; behaviour modification; physiotherapy; and medical and psychiatric treatment of epilepsy and associated mental illness. The period of training ranged from eight months to one year. Children who required medical and physiotherapeutic intervention received this at the district hospital. After intervention, all children were reassessed using VSMS and differences between baseline and final assessment SQ scores subjected to t-tests to evaluate the impact of the intervention programme. Mean SQ values were significantly higher post-intervention for boy and girls in both sites. Pooling results, SQ scores were 41.8 pre and 51.7 post intervention, with the difference being significant for both 0-6 and 6-12 year olds and males and females. As well as benefitting the social competencies of the children, parents' attitudes improved. Whilst they initially had negative attitudes towards their ID child, a positive change was noted after intervention and they felt more confident in their handling of their child.

Sen & Goldbart 2005: Action Research in Urban Slums in Kolkata

Sen & Goldbart (2005) present the processes and findings of a three-year action research project which took place in urban slums in Kolkata, India. Thirteen registered slums and one unregistered slum were visited and 22 children and young adults with disabilities identified. Seven of the children identified had ID. Ninety per cent of caregivers said their child had had no access to education, mobility aids, or special furniture (Sen & Goldbart, 2005). During and after a needs assessment, an intervention programme (which as described as "in essence, a set of suggestions") for physical management, communication, and activities of daily living was compiled for carrying out within the care giver's daily routine. It is noted that most children and adults benefitted from the intervention but information on this is restricted to qualitative noting of positive changes. These suggest that primary caregivers were handling their children more confidently and appropriately for daily living activities, and their expectations of the children appeared to be more realistic. Parents of children with challenging behaviours were particularly pleased as the frequency and intensity of the behaviours had reduced with consistent management strategies and by engaging the child in useful activities. Positive changes in the attitudes of carers are also noted. One example of given for a mother of a child with ID and severe challenging behaviour:

“Initially she used to talk a lot. She would not listen to us. She would also talk to us standing outside the house. We felt she was so stressed that she kept on talking. There has been a lot of change. She listens to us carefully and follows our instructions. She invites us in. We feel she trusts our judgment and wants our advice. She is now also aware of the child’s need for a special school and training in self-care skills. We felt she is also positive about her child’s improvement. Her daughter is also getting involved in the child’s skill training activities.” Page 296-7.

They conclude that the project supports CBR as a feasible approach to providing disability services in resource-poor environments.

Hamblin & Musa 2006: Action Research in Urban Slums of Kolkata

The Indian Institute of Cerebral Palsy (IICP) has initiated CBR services in all 17 districts of West Bengal (Hamblin & Musa, 2006). In Kolkata, IICPs services were based in outpatient centres and few children attended from urban slums. The IICP recognised a need for their services to be extended to children with CP living in the urban slums of Kolkata. In this study an action research methodology was adopted (Hamblin & Musa, 2006). The families of 20 children were given advice or intervention programmes according to the family’s and child’s needs and priorities. Important factors were lack of time, with parents working and programmes having to fit into the daily routine, and the physical constraints of homes which mostly consisted of one small room.

The intervention programmes were designed according to the family’s priorities, while fitting into the routine, time constraints and environmental constraints. A simple goal-oriented intervention programme was devised that could be incorporated into the daily routine. Training materials were developed which were mainly pictorial as many of the people were illiterate. A process of ongoing evaluation was used in line with the principles of action research with observation and reflection being undertaken by researchers in collaboration with fieldworkers and families. The functional abilities of each child were considered in relation to goals set. 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. 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.

Narayan & Reddy 2008: Training of Trainers on ID for CBR Workers

A study in India looked at a “training of trainers” programme on ID for CBR workers (Narayan & Reddy, 2008). They note that a major difference between CBR for people with ID and other disabilities is that people with ID need appropriate training for independent living while people with other disabilities need suitable aids and appliances, assistive devices and guidance so that they can function in society with minimal support. Most CBR programmes, they suggest, have minimal focus on ID.

Twenty three Community Coordinators for Disabilities (CC-D) or Community Development Workers (CDWs) were trained using a manual on ID which included a "Training of the Trainers" package to train the trainers of grass root level workers (Narayan & Reddy, 2008). Participants in the training were tested using a multiple choice questionnaire for knowledge of ID pre and post training. There was a mean gain of 15% in scores (70% pre-test/85% post-test). An impact evaluation was done by listening to reports of each participant. After training they had gained competencies and were able to see progress in people with ID. These essentially anecdotal reports suggest that progress was seen in some areas, with training tips to parents being helpful and the person with ID learning faster. However, it is not clear whether this included any children or adolescents.

Shin et al 2009: Home-based Intervention in Vietnam

A study in a Vietnamese city looked at the effectiveness of a home-based intervention based on the Portage curriculum for preschoolers (Shin et al., 2009). The intervention involved 11 teachers from primary special education schools receiving training to enable them to train parents to work with their children with ID. A total of 30 children aged 3-6 years took part in the study, with random allocation to the intervention (16 children) or control group (14 children). The Vineland Adaptive Behavior Scale Parent Survey Form (VABS) was used to assess development over a one year intervention period with testing at 0, 6 and 12 months. Repeated measures MANOVAs indicated that the intervention group gained more than the control group in the areas of motor skills ($F=3.9, p<.05$) and daily living skills ($F=2.7, p<.05$) over one year. However, as the authors note the small sample limits the power of the research design. Further, the programme could not meet the needs of all children and one child was excluded from the study as their physical disability was too severe for them to receive the intervention service. Nonetheless, Shin et al (2009) suggest that the results demonstrate the feasibility of such early intervention in developing countries. However, the study did involve teachers with some experience of working with children with ID training parents and access to teachers with such experience may be limited in many LAMI contexts reducing the feasibility of incorporating this method as part of CBR.

Summary & Discussion

In the following Table we have attempted to apply GRADE methodology (GRADE Working Group, 2004) to rating the quality of evidence for CBR in relation to children with intellectual disability overall and across the seven outcome domains identified by WHO as relevant to child and adolescent mental health outcomes.

Domains	Quality of Evidence
A. Overall performance at school (including academic performance, participation and behaviour)	Very low
B. Family functioning (includes functioning of the child and the parents)	Very low
C. Adverse effects of treatment	Very low
D. Improvement in physical health, growth and development	Very low
E. User and family satisfaction	Very low
F. Symptoms	Very low
G. Reduction in risk behaviour	Very low
Overall	Very low

As can be seen, the pattern is extremely consistent with ratings of ‘very low’ quality of evidence across all domains (and consequently overall). This does not, of course, mean that CBR is ineffective. At present, we simply do not have sufficient evidence of sufficient quality to form a judgement with regard to efficacy, effectiveness or efficiency.

This situation is the result of two factors. Firstly, 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). Secondly, our general review of the literature indicates that children (or adults) with intellectual disability are rarely mentioned within the existing evaluation literature. This is consistent with the 2003 WHO review of CBR (World Health Organization, 2003) which noted that some groups are marginalized from participation in CBR and that in many countries this includes people with psychiatric or intellectual disabilities. They propose that: “A council of all partners in CBR should also ensure that all people with disabilities are included, particularly people with psychiatric or intellectual disabilities, who are traditionally left out of programmes” (p8). Further, it is noted that: “Certain groups of disabled persons are difficult to include, like those with multiple disabilities and those with intellectual disabilities, so extra efforts are needed to include them. For people with severe disabilities, like severe intellectual impairment, the social dimension is very important. Individuals have the right to live in the community and not in an institution. Communities can provide important support to parents of children with severe impairments, even if nothing specific can be done for the children’s impairments” (p13).

Improving the quality of the evidence base will require greater investment in evaluation and addressing the marginalisation of people with intellectual disabilities in CBR.

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Appendix One: Search Strategy

Searches were conducted using both index terms and word searches. For word searches synonyms for ID were based on the terms for ID as used in the WHO ID Atlas (World Health Organization, 2007) truncated as indicated below (*). These were:

Developmental disabilities (development* disab*)
Intellectual disabilities (intellectual* disab*)
Learning disabilities (learning disab*)
Mental deficiency (mental* deficien*)
Mental disability (mental* disab*)
Mental handicap (mental* handicap*)
Mental retardation (mental* retard*)
Mental subnormality (mental* subnormal*)

For CINAHL and MEDLINE MeSH terms were employed in searches (+ indicates exploded term).

For ID and variants

(MH "Mental Retardation+") or
(MH "Mental Retardation, X-Linked+") or
(MH "Developmental Disabilities") or
(MH "Mentally Disabled Persons")

Low and Middle Income Countries

(MH "Africa+") OR
(MH "Asia+") OR
(MH "Europe, Eastern+") OR
(MH "Central America+") OR
(MH "South America+") OR
(MH "West Indies+) OR
(MH "Pacific Islands+") OR
(MH "Developing Countries")

In PsycINFO index terms for ID were searched as below:

(DE "Mental Retardation" OR DE "Anencephaly" OR DE "Borderline Mental Retardation" OR DE "Crying Cat Syndrome" OR DE "Downs Syndrome" OR DE "Home Reared Mentally Retarded" OR DE "Institutionalized Mentally Retarded" OR DE "Mild Mental Retardation" OR DE "Moderate Mental Retardation" OR DE "Profound Mental Retardation" OR DE "Psychosocial Mental Retardation" OR DE "Severe Mental Retardation" OR DE "Tay Sachs Disease") OR (DE "Developmental

Disabilities" or DE "Fetal Alcohol Syndrome" or DE "Fragile X Syndrome" or DE "Phenylketonuria" or DE "Prader Willi Syndrome" or DE "Rett Syndrome" or DE "Williams Syndrome")

PSYCINFO index terms for low and middle income countries were searched as below:

(ZY "afghanistan") or (ZY "africa") or (ZY "albania") or (ZY "algeria") or (ZY "american samoa") or (ZY "angola") or (ZY "armenia") or (ZY "asia") or (ZY "azerbaijan") or (ZY "bangladesh") or (ZY "belarus") or (ZY "bhutan") or (ZY "bolivia") or (ZY "bosnia-herzegovina") or (ZY "burkina faso") or (ZY "burundi") or (ZY "cambodia") or (ZY "cameroon") or (ZY "cape verde") or (ZY "cape verde islands") or (ZY "central african republic") or (ZY "central america") or (ZY "chad") or (ZY "china") or (ZY "colombia") or (ZY "commonwealth of independent states") or (ZY "comoros") or (ZY "cuba") or (ZY "democratic republic of congo") or (ZY "djibouti") or (ZY "dominican republic") or (ZY "east timor") or (ZY "eastern europe") or (ZY "ecuador") or (ZY "egypt") or (ZY "el salvador") or (ZY "equatorial guinea") or (ZY "eritrea") or (ZY "ethiopia") or (ZY "fiji") or (ZY "gambia") or (ZY "georgia") or (ZY "ghana") or (ZY "guatemala") or (ZY "guinea") or (ZY "guinea-bissau") or (ZY "guyana") or (ZY "haiti") or (ZY "honduras") or (ZY "india") or (ZY "indonesia") or (ZY "iran") or (ZY "iraq") or (ZY "ivory coast") or (ZY "jamaica") or (ZY "jordan") or (ZY "kenya") or (ZY "kiribati") or (ZY "korea") or (ZY "kyrgystan") or (ZY "laos") or (ZY "lesotho") or (ZY "liberia") or (ZY "madagascar") or (ZY "malawi") or (ZY "maldives") or (ZY "mali") or (ZY "marshall islands") or (ZY "mauritania") or (ZY "micronesia (federated states of)") or (ZY "moldova") or (ZY "mongolia") or (ZY "mozambique") or (ZY "myanmar") or (ZY "namibia") or (ZY "nepal") or (ZY "nicaragua") or (ZY "niger") or (ZY "nigeria") or (ZY "north korea") or (ZY "north vietnam") or (ZY "oceania/pacific islands") or (ZY "pakistan") or (ZY "papua new guinea") or (ZY "paraguay") or (ZY "peru") or (ZY "philippines") or (ZY "republic of congo") or (ZY "rwanda") or (ZY "samoa") or (ZY "senegal") or (ZY "sierra leone") or (ZY "solomon islands") or (ZY "somalia") or (ZY "south korea") or (ZY "sri lanka") or (ZY "sudan") or (ZY "surinam") or (ZY "suriname") or (ZY "swaziland") or (ZY "syria") or (ZY "tajikistan") or (ZY "thailand") or (ZY "tibet") or (ZY "togo") or (ZY "tonga") or (ZY "tunisia") or (ZY "turkmenistan") or (ZY "uganda") or (ZY "ukraine") or (ZY "uruguay") or (ZY "uzbekistan") or (ZY "vanuatu") or (ZY "vietnam") or (ZY "west indies") or (ZY "yemen") or (ZY "zambia") or (ZY "zimbabwe")

In all databases, the search terms employed for identifying research relevant to the effectiveness of CBR for children and adolescents were: rehabilitat*; community; service*; interven*.

Appendix Two: The Studies

Study	Country	World Bank Classification	Setting	Sample Size	Design/purpose	Outcome Measures	Results	Other Comments
Arya 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
Hamblin & Musa 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.
Lagerkvist 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

Study	Country	World Bank Classification	Setting	Sample Size	Design/purpose	Outcome Measures	Results	Other Comments
McConachie, Huq, Munir 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.

Study	Country	World Bank Classification	Setting	Sample Size	Design/purpose	Outcome Measures	Results	Other Comments
Menon, Jena, Kumar 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 & Reddy 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 & Lundgren-Lindquist 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
Sen & Goldbart 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, Nhan, Lee 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

Study	Country	World Bank Classification	Setting	Sample Size	Design/purpose	Outcome Measures	Results	Other Comments
Thorburn 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