Rehabilitation of People with Intellectual Disabilities in a Resource Poor District, Barwani, India: A Community-Based Approach

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Jackson State University

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Rehabilitation of People with Intellectual Disabilities in a Resource Poor District, Barwani, India: A Community-Based Approach

Ram Lakhan
Jackson State University

Abstract
People with intellectual disabilities (ID) have several rehabilitation needs, which are difficult to address at one institution. Community-based rehabilitation (CBR) is one approach that provides services that meet their varied needs within their own communities. Objective of this research is to study a community-based rehabilitation program that provides comprehensive rehabilitation to people with ID in India. People with ID were identified through a door-to-door survey in 63 villages of the Barwani District. Patients received medical, educational, psychosocial, and vocational intervention by a CBR team. A total of 262 subjects, 140 tribal (53.4%), 122 non-tribal (46.6%) were categorized as borderline (5, 1.9%), mild (79, 30.1%), moderate (100, 38.1%), severe (63, 24.4%), and profound (15, 5.7%). Patients were both male (138, 52.7%) and female (124, 47.3%). Medical intervention was provided to 100% of study subjects, inclusion to 74 (28.2%), parent training to 204 (77.8%), and disability certificate to 225 (85.9%). CBR is a feasible and acceptable approach in poor rural settings that enables ID people, their parents, and respective communities to promote patient rehabilitation and inclusion.

Introduction
Intellectual disability (ID) is a condition characterized by significant limitations in both intellectual functioning and adaptive behavior (AAIDD, 2013). Intellectual disability not only affects an individual’s overall life, but also their entire family, especially in poor rural areas in India where the availability of rehabilitation services is very limited. The Indian Ministry of Social Justice and Empowerment has implemented several rehabilitation programs across the country, but outreach of those programs is affected due to several structural and practice-related issues. Developed countries including the United States, the United Kingdom, and several European countries utilize institutional approaches to address needs of ID individuals. Highlighted in these systems is a gradual movement toward ID community living (Thorn, Pittman, Myers and Slaughter, 2009). India’s concern surrounding the care of ID people is rising. Therefore, there has been an attempt to develop a more suitable rehabilitation model to serve people with ID (Lakhan, 2013a).

The National Trust Act was established a decade ago with purposes of promoting rehabilitation and facilitating guardianship to ensure legal rights of people with ID. There are numerous and complex issues involved in ID patients’ rehabilitation. The prevalence of ID in India is 2.5/1000 (Srinath & Girimaji, 1999), which is comparable to the reported worldwide prevalence (Mercadante, Evans-Lacko, and Paula, 2009). The high ID incidences in rural India (Narayanan, 1981) are most concerning. Most rehabilitation institutes are located in urban settings; thus their reach to the rural population is limited by distance from home, poor transportation facilities, poverty, and lack of awareness (D’Costa, 2008; Klasing, 2007; Lakhan, 2013a). Poverty, dearth of resources, low awareness, and lack of political reform stunt development of strong policies that positively intervene on behalf of ID patients’ rehabilitation. Therefore, a more suitable and comprehensive approach is needed to address the rehabilitation needs of ID people in India (Ewardraj, Mumtaj, Prasad, Kuruvilla, and Jacob, 2010; Malik & Harbour, 2013).
A previous study found that in poor communities, people with disabilities are identified by their disabilities (Burns, 2000). People with ID have varied rehabilitation needs: they require unique medical, educational, vocational, and social support. It is likely that some medical needs can be addressed through the existing infrastructure; however, attitudes of health workers and even professionals retain a barrier in service delivery. Education, employment, and independent living needs are the critical areas of rehabilitation needed to maximize ID patients’ integration. One would not argue that ID people need equal socialization, educational development, and community inclusion, which are all severely underdeveloped in poor rural communities (Rashij and Trajkovski, 2006; Kumar, Roy & Kar, 2012).

Community-based rehabilitation provides rehabilitation to people with disabilities. The World Health Organization (CBR, 2004) proposed this initiative, which has reported success in developing countries. It includes local resources and local participation (Crishna, 1999), and is ultimately a CBR based social model of rehabilitation that recognizes medical intervention importance. CBR is considered accessible and cost-effective (Velema and Fuzikawa, 2008) and enhances utility to implement resources into poor settings. CBR is flexible and sensitive to the cultural needs (Dawad & Jobson, 2011; Crishna, 1999), and the program can be customized to the local needs and available community resources. Grounds of developing CBR are based on participation and ownership of community at every program stage. CBR can be beneficial for rehabilitating people with ID in developing countries (Mirza, Tareen, Davidson, and Rahman, 2009; Lakhan, 2013b). CBR creates awareness, facilitates service availability, and empowers disabled people, parents, and community through capacity building initiatives. Presently, CBR is popular and being followed in 90 developing countries (Gupta and Singhal, 2004; Robertson, Emerson, Hatton, & Yasmy, 2012; Finkenflugel, Wolffers, and Huijsman, 2005). CBR can be a great option to address the challenges of ID population in resource poor settings (Kumar et al., 2012).

**Setting**

This program was implemented by a non-government organization (NGO) called Ashagram Trust (AGT) located in the district of Barwani in the state of Madhya Pradesh, India. AGT began in 1983 for the purpose of rehabilitating people with leprosy, and then expanded its services to the entire Barwani district and in the other adjoining districts of Khargoong, Khandawa, Dhar, and Jhabua. Barwani is one of the poorest district in Madhya Pradesh, and the Department of International Development (DFID) lists it among the 100 poorest districts in India (Sarma Committee, 1997). Barwani is considered a tribal district because of its larger tribal population (68% tribal, 32% non-tribal) (Census 2011). More than 50% of the district population lives below the poverty line. Health and education facilities are very poor (Lakhan, 2013a; JSY, 2010). Until 1999, this region of five districts did not have any rehabilitation facility. People with intellectual disabilities are living in very poor, unhygienic, and depressing conditions.

Historically, ID has been mythologized in religion and culture and resultantly shaped communications, customs, practices, and behaviors (Smith, 2002). Many themed patients are victim of isolation and stigma due to poor awareness, myths, and misbelieves in communities (Kishore, Nizamie, Nizamie & Jahan, 2004; Kumar, Das, Bhandary, Soans, Kumar & Kotian, 2008).

**Objective:** To briefly discuss the process of implementing a CBR program and evaluate its larger impact for ID people in the resource-poor district of Barwani, India.

**Method**

**Demographic and Sampling**

This research implies participatory action methods and was a long-term extension of a community-based mental health project of AGT that was previously implemented in a few
villages of the Barwani district. Sixty-three villages of the Barwani block were included in the CBR project. Of those, 23 villages consisted of a 99% tribal population, and the remaining villages had a 10-20% of tribal population. After approval of the project, a meeting was conducted with village leaders (Surpanch) at Ashagram Campus (Rain Basira). Participants were oriented about the project and were asked to participate in the program. Consent for data collection through surveys, focus group interviews, and key informant surveys were obtained. The Surpanches of all villages selected for the project were oriented about the project. Professionals on the CBR team, including a psychiatrist, specialist in intellectual disability, psychologist, and physiotherapist collectively developed a survey form. This form included screening schedules for mental illness as well as intellectual, physical, visual, and hearing assessments of the disabled. Communality-based rehabilitation workers (CBRWs) were given one week of training on the survey form and on characteristics of disabilities. Findings of the door-to-door survey were compiled and tabulated. A total of 64,800 people were covered in this survey. The project was financially supported by Action Aid India for 10 years (1999-2010).

**Process of implementation**

**Preparatory Phase**

*This process took 6 months. The CBR team conducted numerous team meetings, most starting in the morning around 8 am and ended around 11 pm. Discussion and idea sharing included funding organization members and disability experts.*

**Team Building:** Professionals included a psychiatrist, clinical psychologist, two specialists in intellectual disability, a speech therapist, physiotherapist, two social workers, an accountant, and a computer operator cum clerk. Five CBRWs employed by the CMHP project were also transferred to the program. These CBRWs visited CBR villages with the professionals. There, they conducted meetings with villagers and asked them to recommend people who could work as CBRWs. Criteria included community acceptance of CBRWs and literacy. Selection criteria were that CBRWs should be able to read and write and have a high school level of education. However, in tribal populations, we could not find people with a high school education, and therefore we compromised with this requirement and recruited a few CBRWs who only had a 5th grade education. Female candidates did not come voluntarily, so we approached their parents / spouse and encouraged them to join the CBR team.

**Data Collection: Consent, Focus Group Discussion & Survey:** Disability data for project villages was obtained from the concerned district department. These data were found to be inaccurate when the CBR team visited project villages and tried to interact with those who were listed on the government list as disabled. The team realized the importance of identifying each ID person living in the community. Two approaches were used: *a) focus group discussion (FGD)*, in which a CBRW and a professional in intellectual disability conducted FGDs, and *b) a door-to-door survey.*

In the door-to-door survey we used a Hindi translation of the “National Institute for the Mentally Handicapped Developmental Screening Schedule (NIMH-DDS)” developed by Madhwan, Menon, Kalyan, Narayan and Subbarao (1988) at the National Institute for the Mentally Handicapped (NIMH) India. The “NIMH-DDS” has three screening schedules designed for specific age groups. Schedule 1 covers children below age 3; Schedule 2 is for 3-6-year-olds; and Schedule 3 is for children from age 7 and above. Schedule 1 compares milestones, while Schedules 2 and 3 have questions with yes or no answers. This screening tool can be used by CBRWs and other lower level disability and public health workers in rural populations in India (Robertson, Hatton and Emerson, 2009). This instrument has great sensitivity (0.79), specificity (0.99), and overall screening accuracy (0.98) (Saroj, 1991).

CBR professionals provided a short FGD training and survey to CBRWs. Training comprised of highlighting features and
characteristics of ID, overview of administration tools, and facilitating group discussions. Village leaders (Sarpunch) were contacted and oriented with the project. Written consent for surveys was obtained from each village leader and from every household that included a disabled person. These politically elected members, Sarpunch, were requested to support the program. During the survey, the CBR team attempted to identify key community persons helpful in initiating the CBR process. Data was tabulated and recorded by computer, and a village-wide list was given to respective CBRWs. All CBR villages were divided into 10 clusters based on respective geography and population, and each cluster was comprised of a 5 village mean (3 minimum to 7 maximum). At least two CBRWs were assigned to each cluster, was and each cluster was supervised by a senior CBRW designated as cluster supervisor.

**Capacity building of professionals and CBRWs:** Each CBR team was qualified to provide rehabilitation intervention in an institutional setting, but lacked understanding of a community-based approach. Thus, they attended other organizations’ workshops to gain exposure to the CBR method and were additionally encouraged to develop their CBR understanding by reading related literature. CBRWs also completed a seven-day training module to identify the needs of ID people, conduct meetings, and offer information on disability related schemes and benefits. CBRWs also shadowed CBRs in other organizations. Working as a CBR involves human interaction at various levels; therefore, understanding the types of human relationships is crucial (Perkins & Tice, 1995) for building a positive attitude. A team must believe that the task in which they are engaged is achievable. CBR team attitudes are pivotal developing mentorship relations with clients (Kendall, Buys and Larner, 2000) and ultimately determine program success.

**Interventional Phase**

*CBR intervention was carried out in four broader areas: medical, education, vocation, and social on three different levels. Levels included the: a) ID individual, b) parents and care takers, and c) community and government officials in terms of advocacy for service delivery.*

**Figure 1**

![Diagram highlighting different components of CBR implementation for ID](image)

**Field Visits:** every member of a CBR team conducted field visits on a regular bases for intervention and program monitoring.

**a) Professional Visits:** Professionals of intellectual disability, also referred to as ID experts, accompanied CBRWs to their field visits. ID experts conducted assessments of ID patients. Each ID person took at least two diagnostic tests: 1) Developmental Screening Test (DST) (Bharatraj, 1998) and 2) Vineland Social Maturity Scale (VSMS) (Malin, 1992). Scores obtained on these two tests were averaged to obtain the IQ of each individual. VSMS provides the social Quotient (SQ), which itself highly correlates (0.80) with IQ on the
Stanford Binet Intelligence Test (BKT) (Kumar, Singh and Akhtar, 2009; Kishore, Nizamie, and Nizamie, 2010; Lakhan, 2014). Experts used DST and VSMS because they can be administered in non-clinical settings. Following the 10th revision of International Classification of Disease (ICD), cases were grouped into five categories of ID: borderline (IQ > 70), mild (IQ 50 – 69), moderate (IQ 35 – 49), severe (IQ 20 – 34), and profound (IQ < 20). ICD-10 based criteria were used due to popularity (Schalock, Ruth, Luckasson, Borthwick-Duffy, Bradley et al., 2007) and wide acceptance across member countries of the World Health Organization (WHO, 2007). ID experts selected intervention goals by consulting with parents and offered such intervention on site in homes with parents present. This process also provided hands-on training to CBRWs. In these visits, both professionals and CBRWs interacted with schoolteachers, Auxiliary Nurse Midwife (ANMs), and other community workers of education and health, who were acquainted with the project and requested to support the program by integrating ID people in existing schemes.

Cases, such as other IQ tests at either the AGT center or in medical camps, to further determine IQ profiles and plan appropriate intervention. Gessells Drawing Test (GDT), Segwin Form Board (SBF) and Indian adaptation of the Alexander Pass Along Test (PAT) were used to obtain a quick estimation of a child’s intellectual functioning. A WISC adaptation, called Malins Intelligence Scale for Indian Children (MISIC), was administered on children attending school because this test covers academic components. The Stanford Binet Intelligence Test (BKT) was used to obtain an estimation of a child’s functioning abilities in different areas of intelligence, such as attention, memory, logic, and visuospatial. The obtained scores were used to plan the intervention. Initially, detailed assessment was conducted using the “Functional Assessment Checklist for Planning (FACP), Language Assessment Tool (LAT), and Behavioral Assessment Scale of Indian Children for Mental Retardation (BASIC-MR). FACP provided an estimation of functioning in areas of self-help and academics, and LAT assessed receptive and expressive communication levels and disorders of articulation, voice, and fluency. The frequency and severity of maladaptive behavior problems were assessed through BASIC-MR. Experts found that these tests provided less significant help in a CBR setting due to their administration time requirements and cultural irrelevance. CBRs principally believe in training CBRWs on simplified rehabilitation techniques and tests to minimize the gap for rehabilitation service delivery between ID and professionals. Due to poor applicability and complexity attached to administration, scoring, and interpretation, the idea of using these tests was abandoned. Experts could not find more user-friendly, reliable, valid, standardized and culturally sensitive tests to apply in a CBR setting.

b) CBRW Visit: CBRWs conducted a follow-up of given interventions at every visit. They also watched and mentored parents administering interventions. Interventions were written in the form of task analyses on case files. CBRWs also spent time with ID children, playing and initiating interaction with other children and community members, to maximize exposure in a natural setting, boost learning and confidence, and socialize within a community. CBRWs visited in hopes of selecting those interested in forming the “village committee” group, a backbone of CBR. Moreover, they approached schoolteachers to discuss the possibility of integrating children with ID into regular schools. Teachers willing to enroll ID children into their classrooms and to receive training on inclusion were noted.

c) Medical Camps: medical camps were organized in Menimata, Chikhliya, Silawad, Palaya, and Talwada-Bujurg villages. These villages were considered cluster villages in the project, and people from 3-4 surrounding villages participated. People with ID were assessed for medical conditions, such as epilepsy and psychiatric illness. A physical examination was also conducted. These camps also served people with other disabilities, such as mental illness. Other rehabilitation services, physiotherapy, speech and language training, and behavior modification were also provided to
the individuals with ID during these camps (Lakhan, 2013b; Lakhan, 2014). Camps were also used for health education and awareness on psychiatric disorders and disabilities to prevent secondary disability. Disability management, prevention, inclusion and employment options were discussed.

**Trainings:** Training and exposure visits were organized for parents, community members, and other government grassroot workers such as ANMs, Aganwadi (workers at integrated child development centers), and teachers to strengthen understanding about identification and management of ID.

a) **Parents and caretakers:** The key strength of CBR depends on its social ecology in which people with disabilities, their parents, and community members are enabled (Sen and Goldbart, 2005; Kuipers and Doig, 2013). ID people are more vulnerable and disadvantaged than other disabled individuals because of their limited cognitive and communication abilities. Most ID people require assistance for personal needs and depend on parents and siblings for care. Parent groups were formed so parents could voice common concerns, share feelings, and morally support one another. These groups were also trained on handling their children, taking care of their personal needs, carrying out rehabilitation intervention, and learning about available government benefits. These trainings were conducted at the AGT center and both parents of ID children were encouraged to attend.

b) **Community:** Strengthening community with knowledge of ID people and their various needs enhances sensitivity towards the entire issue, helping to foster their integration. “Village Committees” were formed by interested villagers willing to work on disability. Committees of about ten people, mostly male, were formed in each CBR village and brought to AGT center for two days of training. Social, environmental causes of ID, government schemes, and advocacy skills were discussed with the objective of strengthening committees with knowledge. Committee members support ID people and their parents by asserting rights toward a disability certificate, education, and equal opportunity for employment.

**Community meetings:** Meetings were conducted consistently once a month in each village from the beginning of the program in 2000 until the end of the project in 2010. The focus of the community meetings changed from time to time. The beginning phase of the program from 2000 until 2004 focused on awareness, capacity building activities of CBRWs, parents and community, medical intervention, disability certificates, and inclusive education. During the second phase from 2004 to 2007, the focus slightly shifted towards developing local leadership and enabling people with disabilities to take leadership roles. During the third phase from 2007 to 2010, an attempt was made to bring community forward to take ownership of the program (Lakhan, 2014).

Individual cases in the process of education inclusion were discussed. Duties were assigned to committee members to meet with teachers. Discussion on income generation activities was also done. ID experts often attended these meetings and facilitated discussion on prevention and management of ID. These community meetings were primarily used to form committees, create awareness, motivate parents, income generation options, and promote health.

**Awareness activities:** Several awareness activities were conducted in the evenings, and in the larger villages in the afternoon on market day. Street play, puppet shows, musical nights, and distribution of pictorial pamphlets were the main activities. Play activities, called “child-to-child activities”, were conducted in schools to sensitize non-disabled children for inclusion of their ID peers in schools and during play in the community. Such activities were adopted.
enthusiastically by children and potentially began to change their mindsets about disability.

**Advocacy initiatives and activities:**
Government advocacy on the ID issue is a key requirement in CBR. People should be enabled and guided through the process so villagers united with ID people and their parents to assert their rights and fight against discrimination and injustice, for which rallies were facilitated. Predominantly, village committees came forward and spoke freely with government officers.

**Results**
See Appendix

**Medical Intervention:** All 262 (100%) cases with or without any associated conditions such as psychiatric disorders and epilepsy received appropriate intervention with regular follow up.

**Vocational Intervention:** Attention was first given to those who were 18 years of age or older. Most parents who had a child with less severe ID were able to involve them in their agricultural work. This involvement provided no monitory gain to the family, but developed a sense of productivity in individuals with ID and a hope to their parents. In several villages, committees turned out proactive and ensured inclusion of ID people in the National Rural Employment Guarantee (NREG) scheme. Committees recommended officers of the scheme to assign ID people simpler tasks such as offering water to workers. No exact statistics are available, but we recall that eight people with moderate to higher ID received a few days of employment under NREG. Few people obtained employment at community centers run by religious groups. The parents of ID children younger than 18 years of age were encouraged to involve them in household chores and other tasks in preparation for employment.

**Discussion**

Physiotherapy as well as occupational and speech therapy were considered part of the medical intervention. At the end of the project, many parents (approximately 70%) were able to carry out stretching, positioning, balancing, and gait exercises for their ID children. They were able to take up smaller goals for language stimulation towards enhancing their comprehension and expression. Parents were also able to identify problematic behavior and their handling of those situations became more supportive and free of punishment. In a few cases, we found that parents were using a reward system for helping their children learn good behavior. Parents understood the importance of regular medication for epilepsy or any other medical problems. Awareness, advocacy, and training developed confidence in parents to approach government hospitals and assert their rights to healthcare and medicine (Lakhan, 2014). CBR attempted to link all cases with government hospitals to obtain appropriate consultation and medication, but only carried out for a small number of cases. Cases involving psychiatric disorders or epilepsy could not obtain medicine from government hospitals, since these hospitals had no provisions to buy such medicine (Lakhan, 2013b). CBR project leaders along, together with parents and village committees, met with district and state government health officers requesting medicine at the district hospital. Until the end of the ninth project year, medicines were provided only by CBR and AGT through oral assurance from government officers for arrangement.

Education for people with ID was not considered important among ID parents and communities. Few teachers contacted in the project’s beginning were not at all aware about the inclusion of ID children. Those who were aware, however, did not have the ability to teach ID with regular students in their classrooms (Parasuram, 2006; Rao, 2008; Lakhan, 2013a; Das, Gichuru, & Singh, 2013; Singh, Verma, Das and Yeh, 2014). As the project progressed and awareness activities continued, the concept of inclusion spread among parents, community, and teachers, which was noted in meetings. Readiness among parents and teachers to enroll ID children in regular school came very late. Several meetings were conducted with district level education officers to facilitate this inclusion. District officers were urged through meetings and even rallies to conduct training for
teachers to build their capacity of teaching ID children in regular classrooms. Few teachers showed willingness for training; those that did completed three days of orientation on inclusion for ID at AGT on CBR cost and became more open and confident in teaching ID children in their classes. A total of 74 children were able to enroll in regular schools. The objectives of inclusion were set up in consultation with teachers and were very low compared to their matched peers. The objectives were as follows: the child feels motivated to come school, learn basic routines, gets an opportunity to interact with peers, learns basic reading, writing (name & address), counting, socialization, and attends school regularly for at least for one academic year. Initial attempts were made to enroll less severe children. Children who could not attend regular schools were enrolled in “Non-formal education” (NFE) centers that were started in communities as an alternate provision for schooling (Lakhan, 2013a). The objective of NFE was to motivate non-school going children through recreational activities in the afternoon or evening when children usually stayed home. A community member recommended by the village committee served in these NFEs and received a small payment to honor their time and service.

Employment is achievable for ID people. Parents can involve their adult children in their own occupation and compensate for time and labor. Keeping employment in an independent setting is difficult even though the PWD act states that all person with disability including ID should be given equal opportunity in job. Practically, ID people require some assistance to perform work related tasks that need to be modified and made simpler. Additionally, they require systematic graduated exposure and consistent reinforcement to transfer into employment. The PWD Act has neither included awareness on this matter nor provided employers any support to modify their infrastructure to accommodate ID people.

CBR has little scope for promoting employment options for ID. Committees that understand the nature and characteristics of ID can compromise with employers to accommodate such workers. In rural areas, where the process is comparatively less challenging than in an urbanized setting, the approach of employing ID people in assisted or sheltered workplaces is feasible.

The biggest outcome of CBR was changing the mindset of people. ID people are stigmatized (Perkisn, Holburn, Deaux, Flory and Vietze, 2002; Jahoda & Markova, 2004; Cooney, Jahoda, Gumley and Knott, 2006; Edwardraj et al, 2010) and almost do not have their own identity in their communities. Many of them are called local names resembling mental disability such as Bholaram (son of God who does not know anything), Budhu (does not know anything), or Ganda (mentally ill). These stigmas are emotionally painful (Beart, Hardy and Buchan, 2005). During meetings and training, a sense of connectivity, belongingness, and respect toward ID individuals were all observed and recorded while interacting with the villagers.

Awareness and capacity building activities in the community helped develop a realistic image of an ID person to their parents, further reducing stigma and discrimination in society and increased visibility and possibility of inclusion. Empowerment leads to inclusion and vice versa, which is a key target of CBR (Arokiasamy, 1993). Moreover, volunteerism is a principle of CBR, but could not be supported in this project, which failed to sustain volunteers even for a month to support activities. CBR practitioners should make appropriate arrangements for compensating their workers for their services.

**Conclusion & Research Implication**

This study demonstrates that through the CBR program, parents can learn rehabilitation skills in medical, educational, social, and communication areas and they can carry out physiotherapy, communication training, and teaching. Parents can also learn to talk with schools to enroll their child. They can also understand the importance of involving their children with ID in household activities in order to prepare them for future occupations. Through
the CBR, parents can also learn some behavior modification skills.

CBR seems to be implementable and an overall beneficial approach in poor rural areas. Its execution requires professional determination, commitment, individual willingness, and flexibility in time, place, and income. This project changed the lives of individuals with ID, their parents, and siblings. Positive changes were noticed in the knowledge, attitude, and practices of people involved, although these changes would need to be quantified via standard tests. As the project is complete after a ten year funding term, a final evaluation is needed to compile results and summarize the project’s impact on the lives involved. Unfortunately, at the end of this project, most professionals left the organization and AGT did not receive funding for a final external evaluation. This process-based article provides a descriptive and structural framework of implementing CBR in rural poor settings.

Results mentioned in this paper were based on reports, data, meeting notes, discussion, interaction between experts and parents, community, CBRWs, and colleagues. The author attempted his best to keep an objective position, but subjectivity cannot be denied.

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Conflicts of interest: none

References


perceived stigma, social comparison and future aspirations. *Journal of Intellectual Disability Research, 50*, 432-444.


Robertson, J., Emerson, E., Hatton, C. & Yasmy, M.T. (2012). Efficacy of Community-Based Rehabilitation for Children with or at Significant Risk of Intellectual Disabilities in Low- and


Ram Lakhan is a Doctoral candidate in public health at Jackson State University. He has a therapeutic degree in intellectual disabilities and is specialized in providing comprehensive therapeutic intervention to people with intellectual disabilities and associated conditions. He has served people with ID, multi-categorical disabilities, and mental illness in diverse communities with resource-poor settings. Mr. Lakhan can be contacted at ramlakhan15@gmail.com.
# Appendix

## Table 1: Profile of ID people who received CBR services

<table>
<thead>
<tr>
<th>Variable/ ID</th>
<th>Borderline ID (IQ&gt;70)</th>
<th>Mild ID (IQ 69-50)</th>
<th>Moderate ID (IQ 49-35)</th>
<th>Severe ID (IQ 34-20)</th>
<th>Profound ID (IQ&lt;20)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Population</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tribal</td>
<td>1(0.38%)</td>
<td>42(16.0%)</td>
<td>57(21.7%)</td>
<td>5(13.3%)</td>
<td>5(1.9%)</td>
</tr>
<tr>
<td>Non-Tribal</td>
<td>4(1.5%)</td>
<td>37(14.1%)</td>
<td>43(16.4%)</td>
<td>28(10.7%)</td>
<td>10(3.8%)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Female</td>
<td>3(1.1%)</td>
<td>39(14.9%)</td>
<td>46(17.5%)</td>
<td>31(11.8%)</td>
<td>5(1.9%)</td>
</tr>
<tr>
<td>Male</td>
<td>2(0.8%)</td>
<td>40(15.3%)</td>
<td>54(20.6%)</td>
<td>32(12.2%)</td>
<td>10(3.8%)</td>
</tr>
<tr>
<td><strong>Socio Economic Status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very Poor</td>
<td>0(0.0%)</td>
<td>30(11.5%)</td>
<td>36(13.7%)</td>
<td>28(10.7%)</td>
<td>3(1.1%)</td>
</tr>
<tr>
<td>Poor</td>
<td>2(0.8%)</td>
<td>35(13.3%)</td>
<td>43(16.4%)</td>
<td>20(7.6%)</td>
<td>5(1.9%)</td>
</tr>
<tr>
<td>Middle</td>
<td>3(1.1%)</td>
<td>12(4.6%)</td>
<td>19(7.2%)</td>
<td>14(5.3%)</td>
<td>6(2.3%)</td>
</tr>
<tr>
<td>Upper</td>
<td>0(0.0%)</td>
<td>2(0.8%)</td>
<td>2(0.8%)</td>
<td>1(0.38%)</td>
<td>1(0.38%)</td>
</tr>
<tr>
<td><strong>Parent Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>1(0.38%)</td>
<td>58(22.1%)</td>
<td>80(30.5%)</td>
<td>52(19.8%)</td>
<td>9(3.4%)</td>
</tr>
<tr>
<td>Primary</td>
<td>0(0.0%)</td>
<td>12(4.6%)</td>
<td>4(1.5%)</td>
<td>1(0.38%)</td>
<td>0(0.0%)</td>
</tr>
<tr>
<td>Middle school</td>
<td>3(1.1%)</td>
<td>6(2.3%)</td>
<td>8(3.0%)</td>
<td>4(1.5%)</td>
<td>0(0.0%)</td>
</tr>
<tr>
<td>High School</td>
<td>1(0.38%)</td>
<td>1(0.38%)</td>
<td>0(0.0%)</td>
<td>5(1.9%)</td>
<td>3(1.1%)</td>
</tr>
<tr>
<td>Bachelor</td>
<td>0(0.0%)</td>
<td>2(0.8%)</td>
<td>8(3.0%)</td>
<td>0(0.38%)</td>
<td>3(1.1%)</td>
</tr>
</tbody>
</table>

## Table 2: Major outcome of the CBR at the 9th year of the program

<table>
<thead>
<tr>
<th>Variable/ ID</th>
<th>Borderline ID (IQ&gt;70)</th>
<th>Mild ID (IQ 69-50)</th>
<th>Moderate ID (IQ 49-35)</th>
<th>Severe ID (IQ 34-20)</th>
<th>Profound ID (IQ&lt;20)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Inclusion</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1(0.38%)</td>
<td>25(9.5%)</td>
<td>81(30.9%)</td>
<td>63(24.0%)</td>
<td>15(5.7%)</td>
</tr>
<tr>
<td>Yes</td>
<td>2(0.8%)</td>
<td>54(20.6%)</td>
<td>18(6.9%)</td>
<td>0(0%)</td>
<td>0(0%)</td>
</tr>
<tr>
<td><strong>Disability Certificate</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>0(0%)</td>
<td>14(5.3%)</td>
<td>17(6.4%)</td>
<td>6(2.3%)</td>
<td>0(0%)</td>
</tr>
<tr>
<td>Yes</td>
<td>5(1.9%)</td>
<td>65(24.8%)</td>
<td>83(31.6%)</td>
<td>57(21.7%)</td>
<td>15(5.7%)</td>
</tr>
<tr>
<td><strong>Parent Training</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>2(0.8%)</td>
<td>13(4.9%)</td>
<td>24(9.1%)</td>
<td>15(5.7%)</td>
<td>4(1.5%)</td>
</tr>
<tr>
<td>Yes</td>
<td>3(1.1%)</td>
<td>66(25.1%)</td>
<td>76(29.0%)</td>
<td>48(18.3%)</td>
<td>11(4.1%)</td>
</tr>
</tbody>
</table>