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RESEARCH ARTICLE

ADDRESSING NEEDS OF THE PEOPLE WITH INTELLECTUAL DISABILITIES IN COMMUNITY BASED APPROACH IN RESOURCE POOR SETTINGS IN INDIA

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ABSTRACT

Background: People with intellectual disabilities (ID), especially living in rural and resource poor settings, face enormous hurdles in receiving the rehabilitation services.

Objective: this study primarily described the planning and interventional approach of community based programs in addressing the needs of people with ID in resource poor setting in India.

Method and Material: the broader planning and interventional approach of three community based rehabilitation projects is described and discussed.

Result: this study found that various needs of people with ID, such as physical, academic, behavioral, social, and occupational can be addressed in community based rehabilitation program by following the bottom up planning approach and community based intervention at three levels: community, family and individual.

Conclusion: community based interventions appear as an option in meeting the needs of ID population especially in resource poor settings in India. Further research is suggested to explore more evidences of its use in ID, and systematize for implementing in various settings with different issues related with ID population.

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INTRODUCTION

Background

Compare to the developed nations, India has almost two time higher population of intellectual disabilities (ID). Being a complex nature of the disability, people with ID need range of services. It is always better for ID population to receive appropriate services in the same setting in which they live and socially interact with others. Due to deficit in cognitive abilities, it becomes relatively difficult for ID people to generalize their learnings from one setting to another; therefore, higher preference should be given to the local and culturally sensitive approaches in order to maximize the effect of services (Patel *et al.*, 2013; Mirza *et al.*, 2009; Wolfensberger, 1972).

Geographically, the higher percentage of ID population resides in rural India. Majority of them belong poverty and because of the poor economic resources, this population have difficulties in availing rehabilitation services (Mirza *et al.*, 2009; Emerson, 2007; Durkin, 2002; Sen, 1992). Government of India is attempting to reach this population by opening rehabilitation centers at district level, but the outreach of these District Disability Rehabilitation Centers (DDRCs) are very limited to

the poor rural population due to many factors (DDRC, India). It is known that most of the rehabilitation institutes are located in big cities and towns and they hardly able to reach to the poor rural population in the nation (Lakhan *et al.*, 2013). On the other hand, these institutes including DDRCs focus on institutional based approach of rehabilitation. In which, it assumed that either individuals with ID receive skill training and use it in their local context after customizing it by themselves, or parent receive training and then impart it to their children with ID in local context.

Conceptually, institutional based approach appears good, but it had lot of challenges and practice implications when it comes for serving in rural areas. High level of financial and technical resources is needed at institute level. While in terms of applicability in rural and even in urban settings, this approach cannot benefit much in area of social inclusion and in reducing the social discrimination against the ID population (Lakhan *et al.*, 2013; Mirza *et al.*, 2009; Mitra & Sambamoorthi, 2008; Lau & Cheung, 1999). ID people including their parents and other family members need psychological and social support. They also need support from their community in overcoming obstacles of ID (Mansell & Ericsson, 1996; Lagerkvist, 1992).

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In contrast to the institutional based approach of rehabilitation; the community based intervention may be more useful in addressing varied personal and social needs of the people with ID. Since, community based rehabilitation (CBR) revolves around the three major components of the society: community, family and individual; thus it may lead better generalization of learnt skills and social inclusion for ID people (Mannan & Turnbull, 2007; Cummins & Lau, 2003; McConnell *et al.*,1997; Turnbull & Boggs,1981; Wolfensberger, 1972).

Compare to the institutional based services, the CBR has been projected less expensive in terms of finances and technical expertise at both ends: CBR implementing organization and community. Probably, the projected qualities of CBR; less expensiveness, acceptability, feasibility, cultural sensitivity and low level of dependency on external resources and specialist inputs, have popularized this approach in many low and middle income countries including India (Reichow, B., Servili *et al.*, 2013; Mannan & Turnbull, 2007; Miles, 1998). Despite of the popularity as an option of addressing needs of ID; this approach has not been standardized enough to the point, where it can be adapted easily. Research is also needed to assess the economic aspects of the CBR and the quality of services (Martelli *et al.*, 2012; Finkenflügel *et al.*, 2008; Finkenflügel *et al.*, 2005).

Objective

The broader approach of planning and implementation of CBR for ID population in resource poor setting in India is described and discussed.

METHOD

This paper is based on the experience gained in implementing CBR projects in a resource poor setting in India through a non-government organization, called Ashagram Trust (AGT). AGT is located in the central India in the state of Madhya Pradesh.

It has been serving people with mental illness, leprosy, disabled and other economic disadvantaged through both approaches: institutional and community based, from past three decades. However, the focus of AGT has been more on CBR in past two decades. Author was involved as a therapist in intellectual disabilities and a project leader for its three major community based projects: 1) *Integrated development of people with disabilities through community based rehabilitation, Barwani*, 2) *Enabling people with disabilities through advocacy and capacity building initiatives, Thikari* and 3) *Community mental health project, Pati*.

RESULT

All three projects were differed in their focus. However, planning and implementation approach was uniform. For planning, bottom up, approach was followed, while intervention carried out at three levels: community, family and individual with ID. Advocacy, networking, collaboration, and administration, are the other important issues in CBR, which were dealt at AGT and CBR team level, and are not discussed here in this paper.

DISCUSSION

Bottom up, planning approach in CBR is not only important for involving the community, but also for the other important factors: awareness, sustainability of the program, resources mobilization and advocacy (Mannan & Turnbull, 2007; Fraser *et al.*, 2006; Castro *et al.*, 2004). Benefit of bottom up approach is widely discussed for CBR. However, its application is very hard and therefore, the evidences of such planning are limited in the research. During initial phases of the community based projects at AGT, CBR team encountered several challenges to adapt this planning. CBR team was feared with the thought that community may present more pressing needs of the community and sideline the issue of addressing needs of the ID population.

Table 1 interventional activities and expected outcome in CBR

Target group	Activities	Expected outcome
Community	Awareness and capacity building activities: Trainings, exposure visits, street plays, community meetings, publication in local newspapers, issue coverage in local electronic and print media	It expected to develop supportive atmosphere for person with ID, reduces discriminative behavior against ID. Community promotes social inclusion of ID in areas of education, employment and in social activities, and customs. Community also learns advocacy skills, acts as pressure group in helping people with ID and their families to receive government benefits.
Family	Need based trainings are imparted to the family members. These training were given to both parents. However, participation of mothers was always higher in CBR compare to fathers due to many reasons. Mainly trainings are focused in the domains of behavior management, personal care, communication, motor, academics and social. Parents are provided information on various schemes and welfare provisions. They are also connected with the other families of ID person in the community.	It expected to increase self-esteem, and develop confidence to take care of an ID person. It reduces psychological and financial burden of parents. Promotes healthy atmosphere in family. It further promotes inclusion of ID person in household activities, academics, employment and in other social activities. Families feel empowered in dealing with government machineries in availing the benefits for their ID children. Families also act out as support system for other families and provide respite care to each other. Families become more aware about the preventive aspects of ID, and they challenge existing negative practices, myths and misconceptions in the society.
Individual	Need based intervention is given to the individuals with ID through the community workers, professional of the CBR team, by involving parents and other local rehabilitation/health workers. ID children are assisted for enrollment in local schools, and adults for participation in ongoing employment programs. They encouraged asserting their rights and participating in household and other social activities in family and community.	It expected that person with ID learn skills in self-help care, communication, academics and behavior. They take care of their personal needs, communicate as per the need and behave appropriately in different setting. They develop self-esteem and feel better in participating in play, and outdoor activities with their age matched peers. This promotes their inclusion in society and reduces dependency on parents. (However, these expectations cannot be uniform with all ID people because of their varied range of abilities and limitations).

In fact, this feeling was predominantly the outcome of inexperience in CBR, and also due to the professional trainings of the CBR leaders/professionals, who had rigorous training on the institutional based model of care or intervention, and lacked understanding on CBR. Result to that AGT found very difficult to move forward with bottom up approach in first year of the plan, however, after the first year, CBR team was fairly effective in involving the community in planning. Participatory Rural Appraisal tool of participatory planning; popularly known with the abbreviation of PRA in India, was used with different themes in all three projects under the bottom up planning approach (Jariwala *et al.*, 2013; Chambers, 1994).

tasks such as carrying drinking water for manual workers, or bringing digging tools from one place to other were identified, for this population, which they were able to do for their employment (Lakhan, 2013b, Lakhan, 2013c). In most cases, parents acted as best trainers for their children. Parental involvement in training of their children with ID is already supported by other researchers (McConkey *et al.*, 2000).

Early identification and intervention is highly recommended for management and reduction of the secondary effects of the intellectual disability. Awareness, in community that also included other village level workers: nurses, disability workers, teachers, para-educators (education friend), and multipurpose health workers, helped in early identification and referral of the children with suspected delayed development to the CBR team or other service providing agencies for the professional evaluation. A study conducted at AGT, in which early intervention was provided by the community workers of all three CBR programs of the organization was found effective (Lakhan *et al.*, 2013; Crishna, 1999). That research translates that the highly technical services of early infant stimulation/early intervention may also be offered effectively in community settings. Apart from ID, community based approach was very effective in treating severe chronic mental disorders, and mobilizing community to create healing atmosphere around the people with mental illness (Chatterjee *et al.*, 2014; Chatterjee *et al.*, 2009; Chatterjee *et al.*, 2003; Bloom, 2009). Chatterjee *et al.* (2014) continued community approach in treating mental disorders/disability in other settings in India. Community based intervention found relatively more effective against the institutional based approach in their randomized controlled clinical trial study (Chatterjee *et al.*, 2014; Mirza *et al.*, 2009).

By looking at the broader planning and interventional approach, the CBR can be taken as an option in addressing the needs of ID persons, their families and communities (Robertson *et al.*, 2012; Kumar *et al.*, 2012; Chatterjee *et al.*, 2008). Since, the CBR programs are highly community oriented, which invite and involve local participation at all levels of planning and implementation; therefore, this approach is useful in spreading awareness, promoting prevention, and management of ID, and advocating for policy changes. Theoretically, CBR is still in phase where lot of experimentation and research is needed (Martelli *et al.*, 2012; Finkenflügel *et al.*, 2008; Finkenflügel *et al.*, 2005). The certain components of the current framework of CBR correlate with several other health promotion, preventive, and advocacy theories. It show fair similarities with ecological approach of addressing needs of ID people in community (Lakhan & Ekundayo, 2013).

Strength & Limitation: this paper is based on the first-hand experience gained in planning and implementing three community based projects which have substantial focus on ID. Strength of this paper is that the programs were implemented in the poorest population in a most backward district of the India, and so far there is no such studies have found. Author has attempted to his level best to support his views with the references of empirical studies; yet, the author's subjectivity

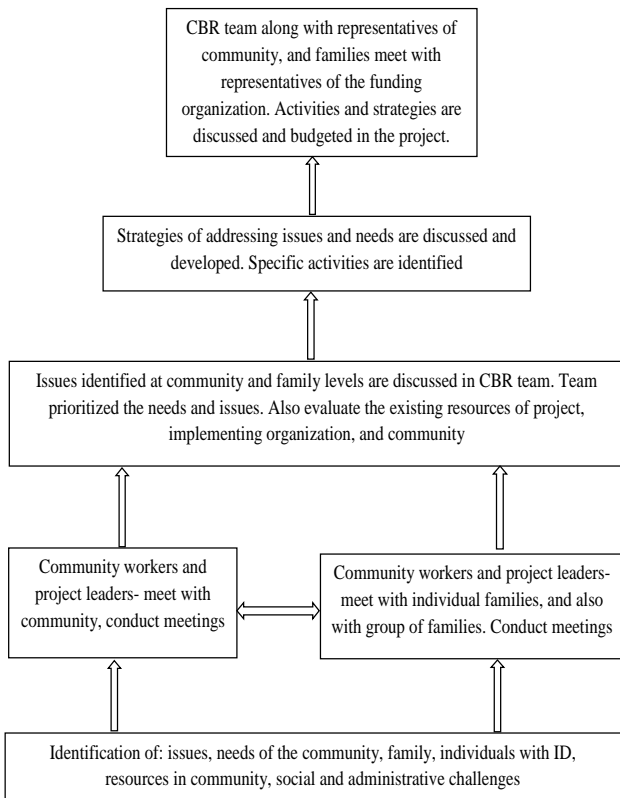


Figure 1 Steps involved in “Bottom Up” approach in the planning of CBR

It was possible to implement intervention at all three levels of the community right from the first year of the program. Individualized intervention, was picked up with great enthusiasm by families of the ID people, followed with community. Individualized intervention was possible and found effective in most of the domains. Behavior management provided by the professionals of the intellectual disabilities through community workers and with the involvement of parents was effective in controlling and minimizing the range of behavior issues (Lakhan, 2014; Rao *et al.*, 1993). The other challenging task was the inclusion of the ID children. CBR team faced resistance from several stakeholders of the program, including the government teachers, who were not properly trained for the inclusion (Bines & Lei, 2011; Singal, 2010). The community involvement in the program and the advocacy skills of parents, which they gained during the program, was helpful in achieving certain level of inclusion with ID children (Lakhan, 2013a). Employment for few people with ID was also possible under the National Rural Employment Guarantee (NREG) scheme with the advocacy and pressure of the community groups on the implementing agencies. Few simpler

cannot be denied, that might have originated for being the participant in the program for 8 years.

CONCLUSION

This study demonstrates that community based rehabilitation approach can be an option in resource poor settings in meeting the needs of individuals with ID and in developing the supportive atmosphere for them to live meaningfully, respectfully, and productively. However, this approach need to be further researched and compared for efficacy, affordability and feasibility against other available options.

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Conflict of Interest: author does not have any conflict of interest arising on this manuscript

References

- Bines, H., & Lei, P. (2011). Disability and education: The longest road to inclusion. *International Journal of Educational Development, 31*(5), 419-424.
- Bloom, E. C. (2009). The Effectiveness of Community Support Systems and Psychosocial Rehabilitation Services for Mentally Ill Children and their Families. *International Journal of Psychosocial Rehabilitation, 14*(1), 4-20.
- Castro, F. G., Barrera Jr, M., & Martinez Jr, C. R. (2004). The cultural adaptation of prevention interventions: Resolving tensions between fidelity and fit. *Prevention Science, 5*(1), 41-45.
- Chambers, R. (1994). The origins and practice of participatory rural appraisal. *World development, 22*(7), 953-969.
- Chatterjee, S., Chowdhary, N., Pednekar, S., Cohen, A., Andrew, G., Araya, R., ... & Patel, V. (2008). Integrating evidence based treatments for common mental disorders in routine primary care: feasibility and acceptability of the MANAS intervention in Goa, India. *World Psychiatry, 7*(1), 39-46.
- Chatterjee, S., Naik, S., John, S., Dabholkar, H., Balaji, M., Koschorke, M., ... & Thornicroft, G. (2014). Effectiveness of a community-based intervention for people with schizophrenia and their caregivers in India (COPSI): a randomised controlled trial. *The Lancet, 383*(9926), 1385-1394.
- Chatterjee, S., Patel, V., Chatterjee, A., & Weiss, H. A. (2003). Evaluation of a community-based rehabilitation model for chronic schizophrenia in rural India. *The British Journal of Psychiatry, 182*(1), 57-62.
- Chatterjee, S., Pillai, A., Jain, S., Cohen, A., & Patel, V. (2009). Outcomes of people with psychotic disorders in a community-based rehabilitation programme in rural India. *The British Journal of Psychiatry, 195*(5), 433-439.
- Community-Based Rehabilitation Approach, India. *Journal of Special Education and*
- Crishna, B. (1999). What is community-based rehabilitation? A view from experience. *Child: care, health and development, 25*(1), 27-35.
- Cummins, R. A., & Lau, A. L. (2003). Community integration or community exposure? A review and discussion in relation to people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 16*(2), 145-157.
- District Disability Rehabilitation Centers (DDRC), Retrieved from: http://www.nimhIndia.org/District%20disability%20rehabilitation%20centers%20_DDRC's_.pdf
- Durkin, M. (2002). The epidemiology of developmental disabilities in low-income countries. *Mental retardation and developmental disabilities research reviews, 8* (3), 206-211.
- Emerson, E. (2007). Poverty and people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13*(2), 107-113.
- Finkenflügel, H., Cornielje, H., & Velema, J. (2008). The use of classification models in the evaluation of CBR programmes. *Disability & Rehabilitation, 30*(5), 348-354.
- Finkenflügel, H., Wolffers, I., & Huijsman, R. (2005). The evidence base for community-based rehabilitation: a literature review. *International Journal of Rehabilitation Research, 28*(3), 187-201.
- Fraser, E. D., Dougill, A. J., Mabee, W. E., Reed, M., & McAlpine, P. (2006). Bottom up and top down: Analysis of participatory processes for sustainability indicator identification as a pathway to community empowerment and sustainable environmental management. *Journal of environmental management, 78*(2), 114-127.
- Jariwala, D., Gamit, C., Shah, H., Chaudhari, V., Kavishvar, A., & Kantharia, S. L. (2013). Health needs assessment by Participatory Rural Appraisal technique. *Healthline, Journal of Indian Association of Preventive and Social Medicine, 4*(1), 74-81.
- Kumar, S. G., Roy, G., & Kar, S. S. (2012). Disability and rehabilitation services in India: Issues and challenges. *Journal of family medicine and primary care, 1*(1), 69-73.
- Lagerkvist, B. (1992). Community-based rehabilitation-outcome for the disabled in the Philippines and Zimbabwe. *Disability and Rehabilitation, 14*(1):44-50.
- Lakhan, R. (2013a). Inclusion of Children with Intellectual and Multiple Disabilities: A
- Lakhan, R. (2013b). Intelligence quotient is associated with epilepsy in children with intellectual disability in India. *Journal of neurosciences in rural practice, 4*(4), 408-412..

- Lakhan, R. (2013c). Rehabilitation of people with intellectual disabilities in a resource poor district, Barwani, India: A community-based approach. *Journal of Contemporary Research in Education*, 2 (1): 36-48.
- Lakhan, R. (2014). Behavioral management in children with intellectual disabilities in a resource-poor setting in Barwani, India. *Indian Journal of Psychiatry*, 56(1), 39-45.
- Lakhan, R., & Ekúndayò, O.T. (2013). Application of the ecological framework in depression: an approach whose time has come. *Andhra Pradesh Journal of Psychological Medicine*, 14(2), 103-109.
- Lakhan, R., Mario, A., Qureshi, F. N., & Hall, M. L. (2013). Early intervention services to children with developmental delay in resource poor settings in India. *Nepal Journal of Medical Sciences*, 2 (2): 149, 55.
- Lau, J. T. F., & Cheung, C. K. (1999). Discriminatory attitudes to people with intellectual disability or mental health difficulty. *International Social Work*, 42(4), 431-444.
- Lau, J.T.F., & Cheung, C. K. (1999). Discriminatory attitudes to people with intellectual disability or mental health difficulty. *International Social Work*, 42(4), 431-444.
- Mannan, H., & Turnbull, A. (2007). A review of community based rehabilitation evaluations: quality of life as an outcome measure for future evaluations. *Asia Pacific Disability Rehabilitation Journal*, 18(1), 29-45.
- Mansell, J., & Ericsson, K. (1996). Deinstitutionalization and Community Living Intellectual disability services in Scandinavia, Britain and the USA. London: Chapman and Hall.
- Martelli, M. F., Zasler, N. D., & Tiernan, P. (2012). Community based rehabilitation: Special issues. *NeuroRehabilitation*, 31(1), 3-18.
- McConkey, R., Mariga, L., Braadland, N., & Mphole, P. (2000). Parents as trainers about disability in low income countries. *International Journal of Disability, Development and Education*, 47(3), 309-317.
- McConnell, D., Llewellyn, G., & Bye, R. (1997). Providing services for parents with intellectual disability: Parent needs and service constraints. *Journal of Intellectual and Developmental Disability*, 22(1), 5-17.
- Miles, M. (1998). Development of community based rehabilitation in Pakistan: Bringing mental handicap into focus. *International journal of disability, development and education*, 45(4), 431-448.
- Mirza, I., Tareen, A., Davidson, L. L., & Rahman, A. (2009). Community management of intellectual disabilities in Pakistan: a mixed methods study. *Journal of Intellectual Disability Research*, 53(6), 559-570.
- Mitra, S., & Sambamoorthi, U. (2008). Disability and the rural labor market in India: evidence for males in Tamil Nadu. *World Development*, 36(5), 934-952.
- Patel, S., Alavi, Y., Lindfield, R., & Kuper, H. (2013). The impact of rehabilitative services in the lives of adults and children with disabilities, in low-income and middle-income countries: an assessment of the quality of the evidence. *Disability and rehabilitation*, 35(9), 703-712.
- Rao, P. H., Venkatesan, S., & Vepuri, V.G.D. (1993). Community Based Rehabilitation services for people with disabilities: An experimental study. *International Journal of Rehabilitation Research*, 16(3):245- 250. DOI: 10.1097/00004356-199309000-00009 *Rehabilitation*, 14(1-2), 79-97.
- Reichow, B., Servili, C., Yasamy, M. T., Barbui, C., & Saxena, S. (2013). Non-Specialist Psychosocial Interventions for Children and Adolescents with Intellectual Disability or Lower-Functioning Autism Spectrum Disorders: A Systematic Review. *PLoS medicine*, 10(12), e1001572.
- Robertson, J., Emerson, E., Hatton, C., & Yasamy, M. T. (2012). Efficacy of Community-Based Rehabilitation for Children with or at Significant Risk of Intellectual Disabilities in Low and Middle Income Countries: A Review. *Journal of Applied Research in Intellectual Disabilities*, 25(2), 143-154.
- Sen, A. (1992). Mental handicap among rural Indian children. *Sage Publications India Pvt Ltd*.
- Singal, N. (2010). Education of children with disabilities in India. Background paper prepared for the Education for All Global Monitoring Report. Retrieved from: <http://unesco.atlasproject.eu/unesco/file/2db055a9-fee6-4856-9c36-1e634c6ea995/c8c7fe00-c770-11e1-9b21-0800200c9a66/186611e.pdf>
- Turnbull, H.R. Boggs, E. Brooks, P.O. and Biklen, D.P. (1981). *The Least Restrictive Alternative: Principles and Practices*, American Association on Mental Deficiency, Washington, DC.
- Wolfensberger, W. (1972). *Normalisation: The Principle of Normalisation in Human Services*. National Institute on Mental Retardation, Toronto.

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