

CBR: a vehicle for Children with Disabilities to a Right and Access to Education

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Abstract

In Ethiopia, most community members attach disability with harmful traditional beliefs and a child with disability (CwD) in the family is considered a disgrace. Hence, parents hide and give care and support to their CwDs to protect their social status.

A CBR project initiated in 1994 focused its services on 484 children with motor disorder (CwMD) as an entry point to the community. 124 of them were easily integrated into regular schools with average four months of combined rehabilitation interventions. The success of the CBR intervention on the 124 CwMD helped parents of children with visual impairment (CwVI) to appreciate CBR services. The remaining 360 CwMD got access to education within 1 – 2 years.

The time variation in achieving educational access depended on the differences in educational and economic level of parents, effectiveness of rehabilitation intervention and access to services.

The success in rehabilitating and integrating CwMD into regular schools became a model for parents of CwVI. The entry strategy – **Easy First**, inspired community members to develop positive attitude towards CwDs and the project to become a comprehensive and cross-disability.

Today, CBR is a vehicle in Ethiopia to creating opportunity and access for integrated education for CwVI and other disabilities.

I. BACKGROUND

Community-Based Rehabilitation program was initiated in Ethiopia in 1994 after 30 years of existence of a mono-disability (medical rehabilitation for children with post polio paralysis) rehabilitation institution. The four boarding schools for the blind in Ethiopia are also in existence since four decades. By then, the population of Ethiopia was about 45

million whereas the current population is 77.4 million (58.14% increase). The rehabilitation institutions and the special schools did not increase in number while the population in need of rehabilitation services grew bigger over the years. As the literacy rate and poverty level of Ethiopia are significantly high thus, factors for impairment and disability are embedded in the social, cultural, environmental and economic aspects. The medical and institutional model of rehabilitation approach that virtually created access to services only for the very lucky few has left the great majority of people with disability without basic services and prospective in life. Until the start of CBR programs, rehabilitation service provision institutions could address only to a 1% of the total rehabilitation needs of people with disability in the country. In addition to the minimum capacity it had, the intervention strategy employed had worst consequences-entrenched negative attitudes towards people with disability, disempowered people with disability themselves and people around them, and, perpetuated harmful traditional practices in the general communities.

II. The useful single steps

The CBR staffs are well aware of the failed hopes of parents and guardians of CwD. The CBR workers understand well that parents and guardians of CwD had invested too much of their time and money searching for cure and appealing rehabilitation results but failed many times. The cumulative failures of parents' certainly led to frustration and bitterness in their life. The understanding of CBR workers on the situations of parents, development level of community and the social fabric is the beginning of all intervention steps in communities.

The important pre-engagement steps:

1. Identify opinion leaders
2. Understand community explanations for causes of disabilities and traditional/local rehabilitation interventions from selected popular leaders and mothers
3. Conduct intensive door-to-door disability and socio-economic status survey. The door-to-door survey focus mainly on obtaining:
 - a. Data on available community resources
 - b. Data on community potential resources
 - c. Data on society's rehabilitation practices, values and behaviors on general health
 - d. Data on past efforts and current situations of each family
 - e. Data on capacities and potentials of services providers
 - f. Data on financial and psychological damages of families with CwD and the impacts
 - g. Data on the perception of community members on disabilities and towards PwDs
4. Discuss the survey findings with all stakeholders
5. Introduce CBR strategy as an alternative approach for community development

6. Plan intervention with the active involvement of stakeholders
7. Mobilize community action especially for the preventive and rehabilitation interventions
8. Work intensively on showing differences in the lives of CwD through planned community based comprehensive rehabilitation intervention and creating role models
9. Embark on creating space and opportunities for parents of CwD, PwD, DPOs and community leaders to involve in all aspects of CBR implementation and gradually manage the programs
10. Activate community resources and coordinate for maximization of intended results
11. Jointly evaluate intervention outcomes and inputs of stakeholders
12. Broaden stakeholders involvement and roles

III. The actions

a. Close investigation to know the situations of individuals, community members and the social environment

A CBR project in Addis Ababa, capital city of Ethiopia, identified among others, 484 children with motor disability by applying the above-mentioned steps.

The CBR project through its initial pre-implementation survey found out that 334 of the children had attended clinics and got required medical/rehabilitation support. However, 150 of the children did not get any sort of rehabilitation. 86 of the children were going to regular and informal schools. 110 were using their appliances irregularly while the 224 were not using the appliances at all. 211 had more than one appliance from different churches and NGOs. 22 were earning their living through shoe shining and street vending. 164 were begging on streets and 210 were at home with their parents without clear plan for career development. 184 of the children were females and the 300 males. The age of the children ranges from 7 – 18 years. 327 are with motor disability due to post polio paralysis and the rest 157 with other types of motor disorder.

121 mothers did not take their children at all either to health service providing places or to schools because they did not see any benefit to the children. 29 parents developed mixed feelings after many unproductive trials for cure through traditional means and decided not to take their CwD anywhere anymore for any intervention.

224 CwD had prescribed appliances but did not use them, and their parents believed that the appliances did not bring much change in functionality of the children, hence, detested and disapproved its use. Additional reasons mentioned by majority of the children and parents for not putting the appliances in use are stated below:

“Most often my peers wonder and ask about the appliances and I am fed up of giving explanations over and over again”,

“I sit and walk in awkward positions when I put on the appliances and people pity me but I hate to be pitied”

“I used the long braces for a week and get broken,

I did not go for another pair of braces because it takes a whole day to get them”

“I and my parents thought the braces would cure me but it did not, I put it aside after few months”

“I look miserable in the braces and crutches”

“I am not able to put the appliances on my child properly”,

“The appliances are rigid and difficult to adjust it with the preferred position of my child and to the available space”,

“I hate the braces!”

“The braces are ugly”,

“The appliances are not fashionable”,

“It easily gets broken”

“I rather feel great without it”,

“I am waiting for surgery since 5 years”,

“It is boring!”

“My father did not approve of wearing the appliances every day”,

“My child hates it and is not willing to go to school while putting on the appliance”,

“My child cannot fit in the chair”,

“He cannot walk on the stairs of the school”,

“My daughter was offended by her classmates once and rejected to use the braces”,

“My child looked unhappy and I had to remove the braces forever”,

“Her uncle advised my daughter not to use the appliances all the time because he believes that it will cause her trouble in her future life”,

“I cannot carry the child on my back to the hospital anymore, he’s put on a lot of weight”, ...

The CBR workers learned about the widespread assumptions and beliefs held by parents and the children themselves on disability and modes of rehabilitation interventions. The CBR workers learned greatly that the beliefs and assumptions of the primary stakeholders have deterrent effect on the use of the appliances.

Furthermore, it was discovered by the CBR workers that the polio and neurology clinics are overloaded and the experts did not have follow-up plans at all. The rehabilitation experts considered their mission accomplished when they did medical assessment, diagnosis and prescribe rehabilitation measures. Only the new and very few old clients come to the clinics and the same cycle of intervention continue – assess; diagnose and prescribe. There is no time and institutional mandate to check on the usefulness or uselessness of the rehabilitation appliances prescribed by the experts of institutions.

b. *The survey findings as a means to plan CBR interventions*

The locally available and useful rehabilitation resources, the consciousness level of parents of CwDs and the CwD themselves and the awareness of community members about disability and PwDs reaffirmed the necessity of introducing CBR approach. Primarily, parents have to be taught differently in order to understand the main causes of impairments and disabilities, ways of preventing the causes of impairments and disabilities, and the benefits of early and comprehensive rehabilitation intervention.

The CBR staff discussed on prioritization of the problems and culturally appropriate ways of intervention mechanisms. Hence, community awareness creation became priority number 1. Simultaneously, coffee ceremony was identified a culturally appropriate means to use it for informal community education. Priority number 2 became coordination of planned CBR program activities primarily with health and education sectors and with community organizations.

Parents of registered CwD, CwD who started treatment and withdrew and CwD who needed urgent referral were the first line targets for the planned awareness creation activities. The objectives of the planned awareness services were to enable parents of CwD and the CwD to make informed decision on rehabilitation needs. On the other hand, preparing service providers to accept and treat those in need of their services was crucial; hence, raising the awareness of the experts about situations of parents and CwD was given high priority aiming at creating smooth service provider - customer relationships. However, it was clear from the outset that there are competing priorities in all sides, which require consistent dialogue and balancing

Mothers of CwD were approached individually to set convenient date and time to all to conduct awareness creation activities. Subsequently the first session was organized for 30 mothers for half a day. The facts and the enlightening information were presented in an appropriate and simple ways in which almost all the mothers were able to express what they value and practice. In the end, all mothers demanded the facilitator (CBR Supervisor) of the awareness raising session for information to access the required rehabilitation services for their CwD. Using the momentum, the CBR workers created the linkages with the service providers, such as, Polio and pediatric neurology clinics, orthopedic workshops, KGs, local informal and primary schools. Similar awareness

raising services expanded the neighborhood based coffee ceremony awareness creation activities as well.

The impact of the awareness creation program was measurable in such a way that 124 CwDs got home based rehabilitation with technical and rehabilitation material support from an institution. Following the completion of the physical and psychosocial rehabilitation process, parents were able to put their children in different levels of schools found in the community in less than 6 months time. This joint action and achievement gave way for mothers to regret the past and celebrate the present. Meanwhile, the success story opened many eyes and minds of community members to revise their traditional beliefs and practices on disability and PwDs. The CBR project started to enjoy community reputation and acceptance. In turn, the enabling environment started to stimulate stakeholders to involve further for enhancing the CBR programs. All the more, the CBR project through the participation of community members created demand for rehabilitation intervention, equal opportunity and access to education, health services and poverty reduction. The demands put forth steadily by parents and CwD for equal opportunities and access to services created sense of responsibility for citizens, which were overlooked due to prioritization. Even more, the formal and informal schools became places to show the capabilities of CwDs that paved ways for peer interaction and social integration.

In the 1 – 2 years of the project life, many more mothers of CwD despite their abject poverty and the '*NO HANDOUT*' maxim of the CBR project became prominent advocates for their children and others with disabilities to access social services. Most importantly, mothers of CwD with their acquired knowledge and basic rehabilitation skills were able to provide basic yet comprehensive rehabilitation services to their children together with the CBR workers.

The quickly empowered mothers of CwD and the CwD set examples for others to strive in a similar or better ways. The word spread like a bush fire. That is why we see today hundreds of children with visual impairment (CwVI) and hearing impairment (CwHI) being identified easily and early. The CwD are not only identified early but benefit more from early intervention such as, through early childhood intervention programs (preschool preparations: ADL; O & M training, Braille and social skills programs).

CwVI that benefited from the CBR programs join integrated education fairly easily. From time to time, the number of CwVI joining regular schools is increasing and they perform better in education and socialization because of good preparation at early age.

IV. Conclusion

Mothers of CwD mainly suffer more from lack of appropriate information than poverty when it comes to enabling their children with disability. Ignorance and poverty are the

most motives for CwDs to be easily neglected by their parents. Through implementation of CBR programs, ignorance of mothers is being replaced by raised consciousness level and poverty by generating income, thus CwD get access to education. That is what CBR workers do - create awareness, train and empower community members.

Poverty and ignorance of parents have the power to worsen the consequences of impairment and the life standard of a CwD.