

EXPERIENTIAL ARTICLES

Community-Based Rehabilitation for Children with Intellectual Disability: Experiences from Endosulfan Affected Areas in India

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Abstract

This article describes a Community-Based Participatory Approach (CBPA) for children with intellectual disability in Endosulfan affected areas of Kasaragod district in Kerala state of India. The CBPA strategy evolved from Community Based Rehabilitation (CBR) and was led by Local Self-Government (LSG) members. It involves a four-pronged approach encompassing family, community, service centres and LSG, with a focus on income generation activities and creation of employment opportunities. The CBPA model considers the cultural uniqueness and limited resources in areas where the unscientific and extensive use of pesticides has led to high prevalence of multiple deformities including intellectual disabilities.

Keywords: *Endosulfan; intellectual disability; Community-Based Participatory Approach; local self-government*

INTRODUCTION

Chemical exposure to unscientific and extensive use of pesticides in agricultural fields and industry along with high levels of pollution are increasingly recognized as causative factors for multiple deformities including intellectual disability in India (Kuruganti, 2005). The poor conditions related to accessibility, availability and utilization of the public rehabilitation services and resources accentuate the vulnerability of persons with intellectual disability in India (Jenkins and Davis, 2006; Kumar, Roy and Shekhar, 2012). In such a scenario, the Community Based Rehabilitation Model (CBR), is widely accepted

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as an effective and inclusive model of rehabilitation services in low and middle income countries. The model has been a pioneer in ensuring the welfare of persons with disability through social integration, equalization of opportunities and rehabilitation within the community

Understanding CBR

The principles of CBR include social integration, equalization of opportunities and rehabilitation. Its primary objective is to improve the quality of life, create a positive attitude towards people with disability and provide assistance for people with all types of disability. This is realized through designing flexible local programmes to ensure community involvement and coordinated service delivery at the local level which involves the aspects of health, education, livelihoods and empowerment of persons with disabilities. Therefore, CBR makes service more accessible to people with disability and their families, in the most cost-effective, democratized and culturally appropriate way (Peat, 1998; Mitchell, 1999; Boyce, 2000).

Nevertheless, rehabilitation programmes based on the community have crucial challenges. The lack of organizational ability and knowledge about disability on the part of community development organizations act as major barriers to integration of services (Thomas and Thomas, 1999). Though persons with disabilities have some representations in the committees, they are rarely involved in policy level decisions. The failure to incorporate the local values and traditions concerning the notion of disability can lead to negative attitudes towards CBR. Apart from these, the lack of funding affects the sustainability of such innovative programmes.

Intellectual Disability in Endosulfan affected areas of Kasaragod

In 1978, the Plantation Corporation of Kerala began aerial spraying of Endosulfan, a highly toxic organo-chlorine pesticide, on its cashew plantations extending over 45,000 hectares in Kasaragod district. The WHO classifies Endosulfan as category 2 pesticide which is moderately toxic and the US Environmental Protection Agency classifies it as a highly hazardous pesticide. Endosulfan can be absorbed in the stomach, skin and lungs, and all bodily areas exposed to Endosulfan are vulnerable (Government of Kerala, 2003). Media reports and later several medical camps conducted by state government confirmed the presence of multiple deformities among the residents in and around the pesticide sprayed area. A

report by Government of Kerala (2011) pointed out that children were the worst affected by Endosulfan, leading to congenital anomalies, mental retardation, cerebral palsy, epilepsy and multiple deformities. Tables 1 and 2 provide data from government studies of 2003 and 2010.

Table 1: Incidence of Disability in Endosulfan Sprayed and Non-Sprayed Areas in Kasaragod

Sl. No.	Health Condition	Sprayed Area	Non Sprayed Area
1.	Mental Retardation	971	83
2	Congenital Anomalies	95	70
3.	Psychiatric Problems	46	33
4.	Epilepsy	37	37
5.	Growth Retardation	25	11

Source: Government of Kerala, 2003, p.16

Table 2: Disabilities Identified in Endosulfan sprayed Panchayats of Kasaragod

Panchayat	Mental Retardation	Cerebral Palsy	Locomotor Disability	Multiple Disability	Other Congenital Anomalies	Mental Illness
Badiedukka	59	4	30	14	0	2
Bellur	24	4	36	16	9	15
Mulliyar	42	6	23	7	5	17
Karadukka	76	4	37	18	8	21
Kallar	88	4	32	4	31	18
Ajanur	74	3	15	6	17	15
Kumbadeja	54	1	25	22	9	7
Kayyar-Chemmeny	33	7	18	65	58	29
Panathady	113	0	36	11	30	4
Enmakaje	56	23	61	35	12	10
Pullurperiya	49	6	54	26	14	15
Total	668	62	364	214	193	153

Source: Health Department Survey, Government of Kerala, November 2010 cited by Irshad and Joseph (2015, p. 64)

Though there are debates on the validity of different studies on the effects of Endosulfan, the November 2010 health department survey is considered as the most comprehensive which identified 2,836 affected persons in 11 panchayats. Further, the lack of health infrastructure, accessibility issues and the lack of capacity of the system to address the needs of affected persons have aggravated the situation there (Irshad and Joseph, 2015). Such an alarming rise in the prevalence of intellectual disability in Kasaragod resulted in public outrage throughout Kerala state.

From 1985, there have been several public protests on the use of Endosulfan. In 1998 the Kerala government temporarily banned the chemical and in 2001, it was permanently removed following a court verdict. The government initiated various welfare schemes for the affected population and one of the significant ones was the establishment of community based institutions for children with intellectual disability called BUDS schools and BUDS Rehabilitation Centres.

The BUDS – CBR Model

The BUDS special schools for children with disability are established in Kerala under the legal mandate of the Persons with Disabilities Act, 1995. The first BUDS school based on CBR model was started in 2004, following the initiative of women members of Kudumbashree (self-help group of the state poverty eradication mission of Government of Kerala). The school had to be closed the same year due to the lack of support mechanisms, and was reopened in 2008 with sufficient changes in the model incorporating local values and resources. In 2008, the new model with Community-Based Participatory Approach (CBPA) was launched, defining the role of every stakeholder and working in liaison with Kudumbashree and respective LSGs. Similarly, BUDS Rehabilitation Centres (BRC) were initiated to cater to the needs of older children with intellectual disability. Presently there are 62 BUDS schools and 83 BUDS rehabilitation centres in Kerala. The components of CBPA include:

- a) **Family:** The role of family is crucial in the habilitation, rehabilitation and management of children/persons with disability. Special neighbourhood groups (NHG) were formed for the mother or female guardian of these children to meet once in a month, discuss issues around the welfare of the children and support the activities of the centre. The centres also have the parent support groups that include local government members, community leaders and parents.

- b) BUDS centre: The BUDS centre provides day care, life skills training, academic training and nutritious food to children with disabilities. The required infrastructure and manpower is provided by the LSG. It is mandatory for the centre to have a rehabilitation worker, assistant rehabilitation worker and a vehicle to take children to the centre. It maintains a staff to student ratio of 1:10.
- c) Community: The support of the community is essential for confronting the stereotypes and discrimination towards children with intellectual disability. The community joins the BUDS management committee under the initiative of LSG body members.
- d) LSG: It provides the salary of the personnel in the centre based on their qualifications, and any recurring assistance. It coordinates the convergence of different governmental schemes, individual sponsorships and ensures the smooth functioning and standards of the centre.

SUCCESS OF THE CBPA BASED MODEL OF CBR

A qualitative study was carried out in villages with large populations of children with mental retardation in Kasaragod district. In-depth unstructured interviews with families of the children, rehabilitation workers and community members were conducted to study the impact of the CBR model. The major findings from the study are discussed below.

1. Perceived need by community and sustainability through LSGs

The BUDS schools and centres were established due to popular people's movements following the after effects of Endosulfan in the community. According to one of the LSG members,

It was our need. I saw them (affected children) for the first time during a health camp conducted by the government. It was difficult to believe that they were human beings. Endosulfan had changed their body shape itself. I could not sleep that night (S, male)

The LSGs took the initiative to form schools for children with intellectual disability without any hesitation. They were prepared to bear the financial liability as most of these children were from economically vulnerable families.

The survey to identify the affected children was conducted by the community members through the Kudumbashree group network. The participatory process continued in different aspects of the school. According to a community leader,

I was part of the survey. When we went for the survey one of the children was chained inside the house. Being the sole earning member of the family, her mother had to go to work after chaining her. She was drenched in urine. Today she had changed so much. I feel happy when I see her now. (S, Female)

Such experiences during the survey brought the community together in pooling resources required for starting the school. These narratives highlight the fact that CBPA based model benefited from the strong support and ownership by the community. It not only mobilized resources for the centre but removed the possible stigma and discrimination of the children in the community. It also ensures sustainability since the local governance structure was given a greater role as a stakeholder in the model.

2. Role played by Special Neighbourhood Groups (NHG) and Parent Support Groups

The special NHGs and parent support groups play an important role in identifying the structural and day to day needs of the centre. Most of BUDS schools were started in the houses of community members, until permanent spaces were allotted by the government. When the food provided by the government fell short, the special NHG members pooled their resources to meet the gap. Parents were able to share their concerns about the children during the weekly meeting. One of the parents said:

I am part of the other NHG (Special NHG) as well. I share my experience in that platform regularly. All these members enquire about my son's progress now. I feel that I am not alone. (S, mother)

Kudumbashree provided training to make the functioning of Special NHGs more systematic. Selection of the staff was carried out by LSG based on government guidelines. Thus Special NHGs act a feedback loop, provide close monitoring of the functioning and meet shortfalls in the day-to-day needs of the centre. This also strengthens the CBPA based CBR model.

3. Inclusive education through BUDS

"We got Medha Patkar (well-known environment activist) to our school with the help of our Panchayat President when she came for a campaign against Endosulfan" (D, female teacher).

Such initiatives by BUDS teachers turned BUDS schools into interactive spaces that increased the awareness of disability in the whole community. The focus of BUDS in ensuring the overall growth of child was evident from the conversations with parents.

I used to send my child to a private school. We could hardly afford it. Then the BUDS schools came and now we are happy about the child. Last day the Principal of the former school came and offered admission without fees. (S, mother)

The role of the centre is not restricted to academic and care purposes alone. The school acts as a coordination centre and conducts activities like sale of products made by the children, the proceeds of which are given to children and their parents. The furniture, food, picnics etc. are arranged through various sponsorships. The continuous monitoring by the rehabilitation worker through home visits has created positive impact. According to a parent,

The teacher visits us regularly and ensures the good environment of my child. Mostly she comes without informing us. So we keep ourselves ready to welcome her. She is very particular about his food and cleanliness. She conducts classes for us also. (M, mother)

The parents see improvement in their child: *“She is the only child for us. After going to school, she learnt how to take care of herself. She helps me in the kitchen now”* (L, mother). Such narratives highlight the fact that the positioning of the community at the centre in providing rehabilitation services can change the nature of institutions.

CHALLENGES OF CBPA

Though CBPA model has facilitated empowerment of many, its constraints need to be understood. The rehabilitation of children with severe disabilities remains a challenge. One of the rehabilitation workers points out the concerns:

The plan of action has limitations when it comes to children with severe disability. But we ensure that the parents are motivated enough. But the ultimate question of they becoming completely independent remains unanswered. The health check-ups are initiated by the PHC (primary health centre), but the therapies are done by the parents themselves through government hospitals. (J, female)

The model also raises the concern of dependency on certain stakeholders in ensuring its effective implementation. It is possible that the programme can be

moulded to suit the interest of stakeholders such as staff, political leaders or the community. The welfare of the staff is compromised in certain places due to the dependency on the LSG. Many children with disabilities have not achieved the desired degree of independence in daily living skills. Persons with mild intellectual disability still face stigma in the job market.

CONCLUSION

The community based participatory approach emphasises understanding the individual as a part of a community. Local ownership and participation of the community ensures the inclusion of cultural uniqueness. The concepts of special NHGs and working through LSG were introduced for the first time through this approach. The issues of limited resources and sustainability were resolved by identifying and incorporating the existing assets in the society, an effort spearheaded by LSG. The lack of organizational ability was met by continuous training and guidance from the Kudumbashree network. The CBPA approach also helped tackle stigma and lack of awareness in the community.

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