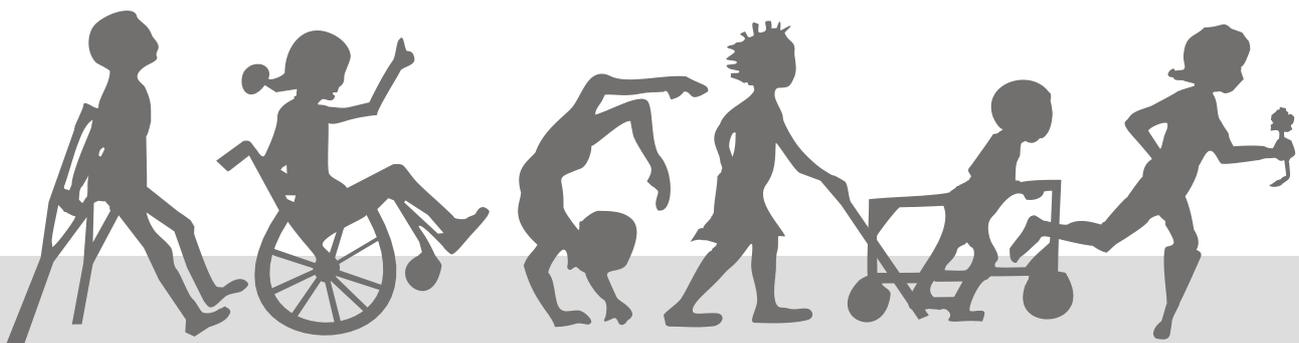


Behinderung und internationale Entwicklung

Disability and International Development



Kinder mit Behinderung im Licht der UN-Konvention über
die Rechte von Menschen mit Behinderung
Children with Disabilities and the UN Convention on the
Rights of Persons with Disabilities





Emancipatory Research on Impact of CBR: Voices of Children with Disabilities

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An emancipatory research, controlled and managed by persons with disability from local communities, looked at different barriers faced by persons with different kinds of disabilities and at the impact of a ten year old community-based rehabilitation (CBR) programme in overcoming those barriers in nine sub-districts in south Karnataka (India). This research also involved 21 children below 15 years. This article discusses the issues emerging from their life-stories, about the barriers they face and the different ways in which CBR programme activities promote access to existing services. The article also raises issues regarding classification of disabilities in the CBR programme.

Introduction

Children with disabilities: Persons with disabilities of all age groups face different barriers to enjoy their basic human rights. For the 200 million children with disabilities in the world, enjoying effective and equitable access to basic social services and meaningful participation in society is yet a distant goal (UNICEF 2007).

Generally speaking, there is limited systematic research related to community-based rehabilitation implementation. Even in that limited research, voices of children with disabilities are rarely heard.

CBR Programmes in Mandya and Ramnagara districts in South Karnataka (India) covering nine sub-districts with a total population of about two million persons, managed by two non-governmental organisations, Maria Olivia Bonaldo (MOB) rural health centre and Sri Raman Maharishi Academy for Blind (SRMAB), were initiated more than ten years ago. This emancipatory research was conducted in these nine sub-districts in Mandya and Ramnagara districts between April 2010 to March 2011.

The CBR activities in the research area are organised in all the five areas of the CBR Matrix (WHO 2010) – health, education, livelihood, social and empowerment. At field level, the two CBR programmes are managed by taluk (sub-district) level *Taluk coordinators* and village level CBR workers. Every CBR worker looks after 25 - 40 villages. At village level, CBR activities are supported by volunteers, usually persons with disabilities themselves or their family members.

Along with home visits, self-help groups (SHGs) of persons with disabilities and their family members are key structures for implementation of different CBR activities. In 2010, the two programmes had 379 SHGs with a total of 5,846 members. Apart from other activities, SHGs are involved in savings and credits as

well as in advocacy activities at the village level.

The SHGs are federated at block level and send representatives to sub-district level to create taluk level Organisations of Disabled Persons (DPOs). The different taluk DPOs are federated into two district level DPOs.

In 2010, the two programmes together reached 23,486 persons with disabilities including 4,815 children (20.5 %) below 15 years in the nine sub-districts.

18 % of the 4,815 children with disabilities participating in these two CBR programmes are below five years of age, including 52.8 % boys and 47.2 % girls. Remaining 82 % are between six to 15 years, including 55.6 % boys and 44.4 % girls. Thus, more male children benefit from CBR programme activities compared to female children.

The 4,815 children are classified by the CBR programme in different groups of disabilities according to the classification used in WHO CBR Manual (WHO 1989) including 7.9 % children with visual disabilities, 18.8 % children with hearing and speech related disabilities, 45.7 % with physical disabilities, 0.3 % with disabilities due to leprosy, 1.5 % with convulsions, 0.2 % with mental illness, 17.4 % with intellectual disability and 9.7 % with multiple or other disabilities.

Emancipatory Research: The term *Emancipatory Disability Research* was first used in 1992 (Oliver 1992) to refer to a radical new approach to researching disability. Emancipatory disability research is based on social and human rights models of disability and includes the following core principles (Barnes 2003):

Accountability to the persons with disabilities and their communities – making sure that persons with disabilities themselves play decision-making role in the research.

Based on the social and human rights models of disability – focusing on the different bar-



riers that create disability as well as on the rights as enshrined in the UN Convention on Rights of Persons with Disabilities.

Should have meaningful practical outcomes for persons with disabilities including empowerment by making sure that the information produced by the research is accessible to persons with disabilities involved in the research.

Emancipatory Research in S-PARK/ CBR initiative (S-PARK/CBR - ER)

S-PARK/CBR (Samagama Participatory Action Research and Knowledge in Community-based Rehabilitation) is a comprehensive research initiative using different and inter-disciplinary approaches to look at impact of ten years of two CBR programmes in 9 sub-districts of Mandya and Ramnagara districts in south Karnataka, India. Emancipatory research in S-PARK/CBR initiative (S-PARK/CBR - ER) is one component of the research, looking at impact of CBR from the point of persons with disabilities living in the communities.

S-PARK/CBR - ER was carried out from April 2010 to March 2011. A total of 28 persons with disabilities representing different kinds of disabilities, including both men and women, were identified and trained to be part of a Research Core Group and facilitators, that planned and implemented this research with support from a Scientific Advisory Group. Research Core Group and facilitators identified a number of priority research themes. On each priority theme a research protocol was prepared that discussed the main key issues and the criteria for identifying the participants. Each research theme meeting was organised by involving 18 - 24 persons with disabilities from the nine sub-districts, ensuring a balance between different factors including gender, age groups, severity of disabilities, education level, socio-economic level, etc. Thus, a total of 17 theme meetings were organised with a total of 369 participants representing persons with different disabilities, including children.

Each research theme meeting was organised around sharing of life-stories by the participants, identification of barriers and facilitating factors in the life stories, impact of CBR programmes, and discussions on what can be done to overcome the barriers by disabled individuals themselves, their families, SHGs, DPOs, CBR and other programmes and by the government. At the end of each research theme meeting a community-video was prepared by the meeting participants, including their messages to other disabled persons and to the communi-

ties regarding the research theme.

Thus, Emancipatory Research in S-PARK/CBR has produced 18 theme reports and videos on different areas of interest to persons with disabilities, that look at barriers and enabling factors for their participation, inclusion, empowerment and effective access to services.

Involvement of Children in the Emancipatory Research of S-PARK/CBR Initiative

A total of 21 children along with their care-givers participated in the research theme meetings of the emancipatory research (5.7 % of all the participants), including 47.6 % male and 52.4 % female. None of these children were below five years of age. The age of participating children ranged from six to 15 years and the average age was 11.6 years. Among them, seven children (33 %) had never been to a school.

Children participated in the following theme research meetings: technical aids and appliances (4), disability and health sector (1), intellectual disabilities (3), physical disabilities (3), multiple and other disabilities (5), speech and hearing disabilities (3), and disability and sports, recreation and leisure (2). There was no theme meeting specifically on children with disabilities and no children participated in the research theme meeting on education.

Disabilities among Child Participants in Emancipatory Research of S-PARK/CBR

According to the CBR programme data about the 21 children participating in the Emancipatory Research, five children were reported to have multiple disabilities (23.9 %), while the remaining children were classified under one of the following disability groups – two children with seeing disability (9.5 %), three children with hearing and speech disability (14.3 %), eight children with physical disability (38 %) and three children with intellectual disability (14.3 %).

All 21 children or their care givers were asked specific questions, if the children had any difficulty in seeing, hearing, speaking, moving any part of the body, loss of sensation, convulsions, learning, strange behaviour and any other problems. An analysis of their answers showed that five children experienced some degree of difficulty in seeing (23.9 %), six children experienced some degree of difficulty in hearing (28.9 %), 12 children experienced some degree of difficulty in speaking (57.1 %), 11



children experienced some degree of difficulty in moving a body part (52.4 %), two children said they had loss of sensation (9.5 %), three children were reported to have episodes of strange behaviour (14.3 %) and 8 of them experienced some degree of learning difficulties (38 %).

Thus, children with disabilities and/or their care givers reported a much wider and variegated *areas of difficulties* compared to the disability classification done by the CBR programme.

Voices of Children and the Impact of CBR

All persons participating in the research theme meetings were explained about the emancipatory research process including the process of making the final video and asked to sign a consent form. They were also asked to select any another name that could be used in the research reports. Both children and their care givers had the possibility to not participate in the video reports. Thus, the names of children used in this article may not be their real names.

Research theme meetings were organised around sharing of life-stories. For some of the children and parents, it was the first time they had come out of their villages or had been together with other children with disabilities. Thus, they were not very articulate in sharing their life stories and explaining the different barriers they faced in their daily lives. Research Core Group members and Facilitators, coming from the same communities, helped the participants to overcome inhibitions by sharing their own life stories as well as by showing videos made by participants in other theme meetings.

For each research theme meeting a report in local language (Kannada) and in English was prepared. The report in Kannada was approved by the participants before the closure of the research meeting.

Issues Emerging from Analysis of Life Stories

An analysis of the life-stories told by the children and their care-givers in the research theme meetings brings out the following issues regarding impact of CBR:

Facing different barriers, lack of information and isolation are recurring themes in most life stories. The following story helps in understanding some of the difficulties faced by disabled children in the school:

Kuvana: "I am the first child to my parents and I have a younger brother. I am 10 ye-

ars old and I am studying in 5th class. I was born with low vision that was detected by my parents when I was three years old and they took me to a specialist centre in Bangalore for check-up. Soon after, I had a brain tumour so I was operated upon. However, this has affected my body and my hands and legs do not function well.

My parents had to struggle a lot to take me to different specialists so that I could regain the functional abilities of my body, but it was not very successful. When I started going to school, initially teachers were reluctant to admit me, but my parents insisted and finally I got admission in the school.

My class mates tease me, sometimes they call me blind or crippled, and sometimes I quarrel with them and complain to teacher. Sometimes I just try to ignore them because I feel confrontation is of no use.

I can see only things that are close and not things that are away. In the class, I generally sit in the fourth row but teachers make me to sit on the first row as they think that from first row I can see the black board. It is not true."

Her mother added, "She writes on her slate and not in the notebook even though she is in 5th class. She is still asked to do first standard lessons, which is my major concern."

Kavana continued, "I am in the CBR programme for almost a year but it has not helped me so much. I started getting monthly pension from the Government, even before coming in the CBR programme."

Two other children who had joined CBR programme only a few months earlier, shared their experiences:

Sushma: "I am 13 years old. I was student of 8th standard but I have stopped going to the school because my class mates used to tease me and to call me names."

Her mother added, "We joined the CBR programme only three months ago, and I have already joined a self-help group. At least, now I can talk to other persons about our difficulties. However, I didn't know that my daughter can also get pension from Government. Her problem is that she gets too angry when people call her names. She starts banging her head against the wall and even the school teachers get afraid."

Rajitha's mother said, "I am very poor.



She is 12 years old but she can't do anything by herself. I have no fixed job, I have to look for some work every day and if I don't find work, how will we eat? My husband left me when Rajitha was born and he found that she is disabled. My son goes to school, so who can take of her all the day? During the break in my work, I have to come home to give her some food because alone she can't even eat. I want to learn about self-help group and also about how to get pension for Rajitha."

In comparison, other children who have been associated with the CBR programme for longer periods, share more positive stories. Most of them receive government pension and are members of self-help groups. Many of them have received technical appliances including hearing aid, modified chair, walker, tricycle, etc. Some of them who need to take regular medicines such as the medicines for convulsions, now know how to receive them free of cost. Their life stories are more confident about the barriers they have overcome and about their rights, as can be seen from the following examples:

Arun said, "I am 15 year old and I didn't hear properly. Now I have the hearing aid and it has improved my communication in the class and with other people. I also receive pension and I am very good at studies."

Sujay said, "I am 11 years old and I am studying in 6th standard. I have low vision like my father and my grandfather. I need to change spectacles frequently. Earlier, we had to buy it in Bangalore and it was difficult for our family. Now I can get my spectacles locally and one pair free of cost every year. I think that government should give more help to poor disabled persons."

Darshan's mother explained, "We took him to so many hospitals but it didn't help him. However, with the modified chair and home based exercises, he is better. We also get small pension for him and I joined a self-help group. CBR programme gave us a sewing machine, and I am working from home as a tailor, so life has improved a little bit."

Zaid said, "I am 14 and my right side of the body is weak. My speech is not very clear and I cannot go to the school. So a volunteer comes home to teach me reading, writing, counting." His mother added, "Because of the volunteer coming regularly, his speech has improved. He is

also a member of taluk level DPO and gets government pension."

Shivananda shared his story, "I am 14 years old. I am short, but I also have fragile bones that break very easily. I frequently hurt myself. I can't walk properly because my knees knock with each other. I am in the CBR programme for six years. I joined school but other children used to make fun of me, so I used to become angry and throw stones at them. Many times, I was punished by the teachers. But slowly my class mates have become used to me, now I have many friends in the school. I also receive pension. There is no self-help group in our village but I am thinking of starting one. I have wheelchair, but someone has to push it and it is difficult. I hope to get a power wheelchair, that will be helpful."

Discussion

Emancipatory research component of S-PARK/CBR initiative has brought out different issues related to impact of CBR programme on children with disabilities.

Accessibility of CBR programme seems to be better for male children compared to female children, and seems to increase with age. This means that comparatively more male children benefit from CBR programme compared to the female children. As no general population survey was done to find out the actual numbers of children with disabilities in the community, the research does not tell us if there are less female disabled children in the community. The research also did not look at specific barriers faced by female children with disabilities in accessing CBR programme activities.

The classification and categorization of children into different groups of disabilities under the CBR programme does not match with the actual difficulties faced by these children in their daily lives. For example, out of total 21 children, only three children were put under "hearing and speech disabilities", while six children experienced some difficulties in hearing and 12 children reported having some difficulties in speaking.

This issue was discussed with CBR workers, who proposed different explanations about why this happens, including issues of stigma in the community, so that persons may prefer to be put under another category that carries less stigma. Another explanation was that certain groups such as persons who have convulsions, are not considered disabled according to the



Indian disability law and thus, these children are often put under a category like intellectual disability that is recognized by Indian law.

The group of persons with mental illness, intellectual disabilities and convulsions seems to be a very mixed up group, where categorization into different groups is difficult for the CBR workers.

Participation of children in this emancipatory research seems to be very limited. Though children below 15 years are more than 20 % of all persons benefiting from two CBR programmes, they constitute only 5.7 % of participants in the emancipatory research. This could have also been due to lack of understanding among the Research Core Group of persons made up of adult with disabilities.

The way this research was organised, it meant that participants have to come to a meeting place for four days. CBR workers were supposed to identify suitable disabled persons in the villages for each research theme meeting, according to the research proposal and selection criteria for participants defined by the Research Core Group.

Discussions with CBR workers showed that it was often difficult to convince disabled persons and their families to participate in the meetings. Many disabled persons had never left their villages and for them going out was difficult. Disabled persons and families could not understand about usefulness of coming to a meeting for four days and be away from home.

For children with disabilities, it raised issues of care-givers to accompany them. Thus, it was even more difficult to convince children with disabilities to join a research theme meeting. For girls, convincing the family to let them go away from home and sleeping outside, was difficult and thus, CBR workers had to spend long time to discuss and convince the families.

Life stories provide vivid examples of the difficulties faced by children with disabilities in the rural areas involved in the research programme, as well as the positive impact of CBR programme in ensuring access to pension, self-help groups and technical appliances. Self-help groups are also platforms for sharing ideas and experiences with other persons facing similar problems and for breaking out of isolation.

Theme research meetings of emancipatory research, also conducted analysis of barriers encountered and strategies for overcoming them. This analysis is not available specifically for children with disabilities.

The emancipatory research, including life stories, is a new important tool to permit to children with disabilities (and their families), in

a research contest, to "have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right" art. 7 of CRPD (UN 2006).

The emancipatory research, in an area where the participation of persons with disabilities and their organization are strong, as in the Mandya and Ramnagara districts in South Karnataka, represent an empowerment tool, supporting the awareness of the condition of discrimination and lack of equal opportunities and promoting recognition of the rights in the community.

Difficulties in involving children in the emancipatory research: Disabled children were usually accompanied by their mothers and sometimes, by other family members, who usually feel that the children cannot express themselves. Therefore accompanying persons tended to speak more and usually it required some effort by facilitators to convince them to allow children to share their own ideas.

Issues of stigma and fear, were associated with the idea of going out of the villages and staying out for the night for 3-4 days meetings, as already mentioned earlier, and thus often families refused to allow their children from participation.

It was also difficult to explain the families the usefulness of participating in a meeting for the research, as the research did not offer them any immediate material benefits. However, once persons did participate in a meeting, they appreciated the opportunity to meet others in similar situations, to learn about different laws and schemes that could benefit from, to share experiences and ideas with others.

Conclusions

Emancipatory research, where persons with disabilities play decisive roles in planning and organising research, can have very strong impact on the way disability-related programmes are conducted. CBR personnel involved in the emancipatory research process has reported wide-ranging changes in the way programme activities are implemented.

Similarly, persons with disabilities and their families involved in the programme, have reported wide-ranging changes in their communities, especially in terms of advocacy activities for access to services and schemes, and for participation in self-help groups and DPOs.

However, this research could get only a limi-



ted involvement of children with disabilities and their families. Even this limited involvement, gives some ideas of the diverse issues that create barriers for the children with disabilities, even more for girls with disabilities. More specific emancipatory research experiences focusing on children with disabilities are needed.

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Zusammenfassung: Eine emanzipatorische Untersuchung, kontrolliert und geleitet von Menschen mit Behinderungen aus lokalen Gemeinden, betrachtete verschiedene Barrieren für Menschen mit unterschiedlichen Behinderungen und die Auswirkungen eines zehn Jahre alten gemeindebasierten Rehabilitationsprogramms (CBR), welches diese Barrieren in neun Unterbezirken von Süd Karnataka (Indien) zu überwinden versuchte. Die Untersuchung umfasste

auch 21 Kinder unter 15 Jahren. Dieser Artikel erörtert die Problematiken, die sich aus ihren Lebensgeschichten ergeben, die Barrieren, denen sie begegnen und die verschiedenen Wege, in denen CBR Programmaktivitäten Zugang zu existierenden Diensten fördern. Der Artikel spricht auch die Klassifikation von Behinderungen in CBR Programmen an.

Résumé: Une analyse émancipatrice, contrôlée et dirigée par des personnes handicapées de communautés locales, considéra plusieurs barrières pour les personnes avec différents handicaps ainsi que les répercussions d'un programme de réhabilitation à base communautaire (CBR) vieux de 10 ans et essaya de surmonter certaines de ces barrières dans 9 sous-régions du sud Karnataka (Inde). L'analyse comprend également 21 enfants âgés de moins de 15 ans. Cet article débat de problématiques qui résultent de leur projets de vie, des barrières qu'ils rencontrent et des différents chemins par lesquels le programme d'activités du CBR favorise l'accès aux services existants. L'article aborde aussi la classification des handicaps au sein des programmes du CBR.

Resumen: Este investigación emancipatoria, controlada y dirigida por personas con discapacidad de diferentes comunidades locales, enfoca las barreras que trató de superar un proyecto de Rehabilitación en Base a la Comunidad (RBC) en los últimos diez años en nueve distritos de Karnataka del Sur (India). El artículo cuestiona las problemáticas que se encuentra en las biografías de 21 niños menores de 15 años y los diferentes caminos en los cuales RBC ayudó a abrir acceso a servicios existentes.

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