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Life stories of persons with intellectual disabilities in Mandya District, India

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This paper is about sharing of life stories of persons with intellectual disabilities as part of an impact assessment of a community-based rehabilitation (CBR) project in rural Mandya District, Karnataka, India. It aims to facilitate persons with intellectual disabilities to look critically at their own lives, to identify the barriers they face and the strategies they adopt to overcome them, including the role played by CBR in this process. An emancipatory research approach was adopted. A residential meeting of 23 persons with intellectual disabilities was organised. The meeting was facilitated by a group of persons with disabilities from the local community who were trained as researchers. Meeting participants shared their life stories and then, with the help of researchers, together analysed those stories, identified barriers and discussed strategies for overcoming these barriers. The research showed that persons with intellectual disabilities faced huge barriers, especially attitudinal barriers, which affected different aspects of their lives. Families and local communities played a key role, both in creating the barriers and in overcoming them. While the CBR project played a supporting role, institutional referral support services were limited and very difficult to access for this group of persons. Emancipatory research approach through sharing of life stories can be useful among persons with intellectual disabilities. It can provide details about the challenges facing these persons and their families, and promote local action to mitigate those challenges.

Keywords: community-based rehabilitation; intellectual disabilities; story telling; emancipatory research; Mandya District; Karnataka; India

Introduction and background

Community-based rehabilitation (CBR) was originally promoted as a rehabilitation strategy for persons with disabilities in low and middle income countries by the World Health Organization (WHO) following the declaration of Alma Ata on Primary Health Care in 1978 (Helander 2007). As evidenced by the CBR Matrix (WHO, 2010), over the past decades, the scope of CBR has gradually expanded to a multi-sectoral community development approach involving health, education, occupation, social participation and empowerment domains. A WHO report on rehabilitation services in 29 countries in Africa (WHO, 2004) shows that during the 1990s, many countries adopted a national CBR strategy, even if the actual coverage of their CBR programmes was often limited. According to another survey done by the WHO in 2011, there were CBR programmes in 96 countries and many countries had adopted CBR as their national strategy for rehabilitation (Deepak 2011: 8). However, in spite of the expansion of CBR programmes in a large number of countries, the evidence-base on the impact of CBR on the lives and well-being of persons with disabilities remains limited. The first World Disability Report (WHO & WB, 2011: 10) identified different disabling barriers faced by persons with disabilities, including the lack of evidence about the effectiveness of CBR programmes. A Delphi study involving CBR experts from different countries emphasized the importance of giving a voice and control to persons with disabilities during the evaluation of CBR programmes as essential to address these issues (Grandisson 2015: ii). The literature rarely addresses good practice for qualitative research that aims to give a voice and control to people with profound and multiple learning difficulties (Nind 2008: 4). Therefore, academic literature about qualitative research involving persons with intellectual disabilities is limited, even more so in the context of CBR programmes in developing countries.

The field of emancipatory research (ER) is a notable exception. The roots of ER go back to participatory research approaches. Persons with disabilities play a leading and decisive role in this approach, which seeks not only to generate new knowledge, but to actually remove barriers and promote social inclusion and equality (McColl 2013: 73). In the context of disability research, ER grapples with questions such as: Who controls the research and how it will be carried out? How are disabled persons involved in the research? What are the opportunities for disabled persons to criticise and influence the research? What happens to the products of the research? (Barton 2005: 320). Despite the potential of ER approaches to help address the evidence gap about the impact of CBR programmes in a manner that is consistent with the social inclusion and empowerment aims of the strategy, ER approaches with the involvement of diverse groups of persons with disabilities have been mostly implemented in the context of developed countries while their application in developing countries, and specifically in the context of CBR programmes, remains extremely limited.

By involving persons with disabilities in playing active role in the research and by taking steps to involve wider community in this can help in this process, ER can help in creating shared local knowledge so that communities can be mobilised to take action. Local knowledge is a collection of facts and relates to the entire system of concepts, beliefs and perceptions that people hold about the world around them. This includes the way people observe and measure their surroundings, how they solve problems and validate new information. It includes - common knowledge, known widely in the community; shared knowledge, known to many but not to all; and specialised knowledge, known to a few persons (FAO, 2005: 7-9). Persons with disabilities and families have individual knowledge about what it means to live with those conditions and about the impact of the interaction between those disabilities and the local contexts. However, usually such knowledge remains limited in the families, especially when the disabling conditions are associated with social stigma, discrimination and exclusion.

A multi-disciplinary research project on the impact of a ten-year community-based rehabilitation (CBR) programme in the Mandya District, south India, was carried out from 2009-2012. This research included both quantitative and qualitative components. The qualitative component of the research was based on an emancipatory approach, and was carried out from 2010-12. It was conducted by researchers who were themselves persons with disabilities living in the same district. It included peer-sharing of life stories of persons with disabilities in a group setting, focusing on the disabling barriers they faced in their daily lives and the strategies they adopted to overcome them. This paper is about the disabling barriers faced by a group of persons with intellectual disabilities involved in the Mandya CBR programme that emerged during the peer-sharing of their life stories.

Research area and context

In 2010, CBR programme funder, the Italian Raoul Follerau Association (AIFO) launched a qualitative research project on the impact of its Mandya CBR programme, using an ER approach. Mandya District is a predominantly rural area in Karnataka state in south India. The total population of the district is around 2 million persons. The CBR programme covering this district was initiated in 1997 and was carried out by two NGOs – Sri Raman Maharishi Academy for Blind (SRMAB) and Maria Olivia Bonaldo (MOB) Rural Health Centre. Its key activities included home visits, support for setting up of self-help groups (SHGs), and facilitating access to disability certificates and related benefits such as technical appliances and pension. These activities were carried out in the field through 60 CBR workers, many of whom were persons with disabilities. In total, Mandya CBR programme activities directly involved around 25,000 persons with different disabilities from the district.

Research on the Mandya CBR programme was initially framed as a stratified cluster random survey including a control group, which was carried out in 2009-2010 (Biggeri M., Deepak S. et al, 2012). While this research was being completed, consultative community meetings were organised with persons with disabilities, to understand their views about the impact of the CBR programme. During the meetings, persons with disabilities and their families emphasised the innumerable disabling barriers they faced in their daily lives and the diversity of stakeholders that positively and negatively influenced those barriers.

The proposal for carrying out qualitative research focusing on disabling barriers and the role of different stakeholders, including the CBR programme, in creating and overcoming those barriers, evolved from these meetings. Subsequently, the methodology of ER was developed in collaboration with representatives of persons with disabilities, including those who were working with Mandya CBR programme. The core idea was that the research would be controlled and carried out exclusively by persons with disabilities from local communities, including those persons who were working in the CBR programme. Different qualitative research methods were discussed and finally an approach based on sharing of life stories among peer groups of persons with disabilities in a residential setting was finalised. It was also decided that the research would be carried out in the local language (Kannada). The objective was to facilitate persons with different disabilities involved in the CBR programme to look critically at their own lives and to understand the barriers they faced, the role played by different stakeholders in creating, reinforcing and overcoming those barriers, and to see if this knowledge can help them in bringing changes at different levels to reduce the barriers identified.

Research methodology

The qualitative research took place in two parts.

1. The first part included 16 residential meetings, each involving 20-25 persons with different disabilities from different parts of the district, who had given informed consent for participation, approximately 330 people in total. Each meeting included sharing of life stories in a group setting, a collective analysis of those life stories to identify disabling barriers, group discussion of the role played by different stakeholders in creating, reinforcing and overcoming those barriers, and the preparation of a video film to share what they had learned from their discussions. The preparation of the video films was carried out by persons from the local communities in the local language, using locally available low-cost technology. The informed consent for the research included a separate consent for participation in the video and its subsequent projection in local communities.

2. The second part of the research included 8 decentralised group discussions involving a total of 118 people in SHGs and local communities, about the lessons learned from the residential meetings. Organisation of video-film projections for local community leaders was also carried out at these meetings, if desired by the participants. Forty village-level video-film screenings were subsequently held, each involving approximately 25-30 people.

Both aspects of the research were conducted by 26 persons with disabilities, including persons with mobility problems, vision and/or hearing difficulties, and persons with disabilities due to leprosy and mental illness, who were identified by SHGs in the villages, the local district disabled persons organisation (DPO) and CBR programme staff. (There were no persons with intellectual disabilities on the research team). The researchers were from different socio-economic and educational backgrounds. For example, they included both persons with university degrees as well as some, who had no education. Fifty percent were women. The researchers were provided training in the basics of research, relevant methods, including interviews and focus group discussions and reporting, as well as social and human rights models of disability, biases in research, ethics, privacy and confidentiality issues and the life-stories approach. A ten member Scientific Advisory Group was also created, including academic researchers and representative of national DPOs. Its role was to advise the local researchers and to provide them with periodic feedback to guide the research. The research protocol was approved by the ethical committee of the AIFO.

For each meeting, the local researchers defined locally specific criteria for the selection of participants. Based on those criteria, for each meeting a purposive non-random group of participants was identified with assistance from the SHGs, with the aim of bringing together a diversity of viewpoints and life-experiences relevant to the theme of each meeting. All the meetings were held in a central and accessible location. All the costs for the travel and stay of participants were covered by the research project funders (see acknowledgements). However, no other incentives were provided. More details about the research methodology have been published in a separate paper (Deepak S., Kumar J. et al, 2013).

Residential meeting of persons with intellectual disabilities

This paper is based on the report of a 4-day long residential meeting held in 2011 during which a group of persons with intellectual disabilities gathered with their families to talk about disabling barriers in their lives. It focuses exclusively on the issues raised during the peer-sharing of life stories of these persons during the meeting and their discussions during their collective critical analysis of those stories. The special focus of this meeting on persons with intellectual disabilities was considered vital by researchers as, during 2011-2012, Mandya CBR programme involved a total of 24,646 persons with disabilities, 11.75% of whom had an intellectual disability. Overall, 52% of persons with disabilities were male and 48% were female. About 32% were children below 15 years of age.

The following criteria were decided by the researchers for the identification and selection of participants to this meeting:

- Parents of children with intellectual disabilities

- Persons with intellectual disabilities who are able to express themselves (also with help of accompanying persons or translators)
- Persons with intellectual disabilities who are members of Self Help Groups (SHGs) and/or DPOs
- Persons with intellectual disabilities (even from outside Mandya district, including from national or state level DPOs) who had achieved success in completing studies or were working, who could serve as positive role models
- Representatives of the state level organisation or federation of persons with intellectual disabilities (a disabled person himself or herself, and not a family member)

Information about the meeting and about the criteria for the selection of participants was shared with CBR workers, DPOs and SHGs in villages, asking them to suggest participants from different sub-districts of Mandya.

Meeting participants

Convincing persons with intellectual disabilities and their families to come to this meeting was a long and arduous process, as most of these persons had never been out of their homes and villages. Therefore, many persons originally suggested for this meeting, did not accept the invitation to participate. It was one of the most difficult meetings to organise for this reason. Eventually, 23 persons with intellectual disabilities took part in the meeting, including 11 males and 12 females. The youngest participant was 12 and oldest participant was 35 years old. 13 meeting participants (56.5%) were accompanied by a family member. 85.6% of the accompanying persons were mothers.

Among the participants, more than 65% (15 persons) had no education or only a few years of elementary school education. Only 17% (4 persons) had 8 years of schooling, while none had completed high school. More than 90% (21 persons) had no work or did unpaid work (mainly helping at home). Only 2 persons (8.6%) had a work for which they received a salary. According to Mandya CBR programme, in 2 persons the intellectual disability was classified as “moderate”, while in the remaining 21 persons (91%) it was classified as ‘mild’. Apart from the intellectual disabilities, 4 persons also had low vision, 1 had hearing difficulty, 5 had communication difficulties, 1 had loco-motor difficulty and 1 person had convulsions.
14 participants (60.8%) were members of SHGs in their villages while 5 persons (21.7%) were members of the local DPO. Some 5 persons with other disabilities took part in the meeting as researchers, including 2 persons as meeting facilitators and 1 person as meeting rapporteur.

Results

Life-stories of persons with intellectual disabilities

After the introductions, the meeting started with the sharing of life stories, sometimes with the help of the accompanying persons. The researchers facilitating the meeting tried to ensure that the life-stories touched on different barriers they faced in their daily lives, including in the families, in communities, in accessing health and education services, in finding work, and in social relationships. Extracts from two life stories shared at this meeting are presented below as case studies as they bring out some of the common barriers faced by persons with intellectual disabilities in Mandya district. Names of the persons have been changed to protect their privacy and the stories have been edited to improve their readability.

Arun Kumar (life story told with the help of his mother): ‘I am a 19 years old boy and I live in Maddur sub-district. I have studied up to 7th standard. I had some difficulties in the school, as I was slow in studies. I had failed the exams many times. Last year, the school teachers said that I was already too old for taking the Board examination of 8th standard, so they asked me to stop coming to the school. This made me very sad. I had many friends in the school and I liked playing with them. My mother went to fight with the school teachers, and finally they accepted that I could continue to attend the class of 7th standard. I loved going to the school. I did a lot of work there. For example, I filled the drinking water-pots and watered the garden plants.

Then, a family friend advised my mother to send me to a hostel of a residential centre. I went there but I did not like living there. I had some fights with other persons living in that hostel. They called the police. The police took me to a remand home in Mysore [Centre for juvenile criminals]. I stayed there for a few days. Then my mother came there to take me back to home.

I would like to work, to earn money and to become a rich man. I have a younger sister. After she will get married, I also want to get married and have my family. Now every day I go to work in a bakery. I go in the morning and work there till evening. I earn money. There are some bad persons in our community. When they see me, they call me with bad words. So I also shout at them and abuse them.

I am also part of the CBR for the last seven years. I am a member of self-help group in our village and my mother goes to all the meetings. I am also a member of the DPO but I don’t go to their meetings because I don’t like them. I have the disability certificate and I get monthly pension from Government. My mother takes care of the money for me. She also helps me to get dressed and eat.’

Arun's mother added: 'Arun is very strong. He can walk for long distances and he can go anywhere. But he does not like travelling in a bus. He feels afraid that the bus will take him to some faraway place where he will get lost and never find his way back to the home. He works in the bakery but the bakery-owner does not treat him well and does not pay him a proper wage. Arun cannot count properly. For example, the bakery-owner will give him ten rupees and later tell that he had given him hundred rupees. CBR had also helped us to get a loan from the bank, which we have already paid back. They had also sent Arun for a vocational training course on making candles.

My biggest problem is that in the village he fights with other persons and shouts bad words to them. They complain to me about him all the time. I don't know what to do with him.'

Ramani Kumari (life-story told with the help of her father): 'I am a 12 years old girl and I live in Chennapatna sub-district. I go to the school, I am studying in the 4th standard. But the teacher makes me sit in one corner, because she says that I am not good at studies. I also get convulsions some times. I like to play with children but the other children do not want me. I go to the village *anganwadi* (nursery school) to play with children but the teachers of *anganwadi* do not want me. They say that I am too old for the nursery school.

Some years ago, my father took me to a centre in Mysore for the treatment of convulsions. The doctors told my father that I had to stay there for three months to have full check-up and treatment. As we did not have enough money to stay there, so we came back without treatment. At home, my mother, my elder brother and his wife, they all say bad things to me. Sometimes they beat me. They never want to take me with them anywhere. When they go to a temple or a marriage, they do not want me. Only my father helps me and he takes me out with him. I can do everything. I wash my teeth, I take bath, I dress, and wash my clothes. I also do cleaning in the house.'

Ramani's father added: 'Ramani gets upset very easily. When someone says bad words to her, she starts banging her head on the wall and other children become very afraid of her. She cannot read or write, she cannot count and she does not know the colours. We joined CBR 2 years ago and CBR workers sometimes do play-exercises with her. They say that she should play with other children, but we can't find other children who want to play with her. She has a disability certificate and gets a monthly pension. She is a member of a self-help group and I go their meetings. But I am worried about her. What will happen to her after me, who will take care of her?'

Common barriers faced by persons with intellectual disabilities

After all the participants had an opportunity to share their life stories, the researchers and the participants together reviewed those stories to identify the major barriers they faced in different life domains, and the positive and negative examples of dealing with those barriers. They also discussed the role played by different stakeholders in dealing with those barriers including the roles played by CBR, DPO, village and district institutions. Most common difficulties in the life stories were problems related to the families and to relations with the neighbours and other community members. Issues related to difficulties in finding employment and lack of income were also frequent in the life stories. Family members accompanying the persons with intellectual disabilities often shared their difficulties in accessing services based in cities. They also expressed worries about the future in terms of who would take care of these persons. The following main issues emerged from these discussions:

Family attitudes and relations

Often family members of persons with intellectual disabilities had negative attitudes and they used derogatory words about them. Sometimes there was physical and sexual violence in the family. In many stories, siblings did not want them in the house or they did not want to give them food. Families also did not want them to get married. When married, often their spouses mistreated them or became violent or abandoned them. Families also felt ashamed of the negative reactions from the neighbours, relatives and other persons in the community. Often these persons did not want persons with intellectual disabilities to go out, participate in functions, and make friends. While some family members were against them, usually there were some other family members, especially parents, who took their side and tried to protect them. Without the support of such family members, life would have been very difficult for most persons with intellectual disabilities.

Inheritance-related issues and getting a share of family property were a frequent problem, often leading to fights with siblings. Different persons explained that they had to go to the court to get their share of inheritance. Since courts take long time and require money, this created additional burden on them. Sometimes SHGs and CBR programme supported them in getting their share of inheritance.

CBR workers helped persons with disabilities in the communities by talking to family members, creating awareness and building community pressure for better treatment from the families. They also helped them in developing self-confidence for going out of the home and making friends, for getting married, reporting maltreatment to the police and for gaining their share of the inheritance.

Economic and work-place difficulties

Life stories brought out the difficulties or impossibility of finding paid employment for persons with intellectual disabilities. If they found a job, often they were not paid or paid very little. Employers exploited them. Emotional, physical and/or sexual violence at the workplaces, was also an issue in some stories. Through the CBR project, many had been able to receive disability certificates and received monthly pension. However, very often their pensions and incomes were controlled by other family members. Family members also went to SHG and DPO meetings, and took loans on their behalf. Persons with intellectual disabilities usually agreed with such arrangements if those family members were supportive to them. In a few stories, abusive family members took control of their pensions and other benefits, which was a source of frustration to them and for which, help of CBR workers and other community persons was sought.

Attitudes of the communities

Negative attitudes of the communities including those of neighbours, peer groups and sometimes even teachers and health workers, was a common problem raised in almost all life stories. Often persons in the community used derogatory words like mad, stupid and crazy as nick-names to call them, which was very hurtful. Almost invariably, people in the community did not understand the differences between intellectual disabilities and mental illness. Persons in the communities usually believed that the families of person with intellectual disabilities had some genetic defects, so no one wanted to marry any person from their families.
Even teachers and health workers usually did not understand the issues and often used derogatory words while referring to persons with intellectual disabilities.

Persons with intellectual disabilities did not know how to deal with derogatory words and discrimination in the communities. Families and CBR workers usually asked them to ignore persons using derogatory words. Sometimes they reacted with anger and violence. Often they also used abusive language. Sometimes, to protest the behaviour of other persons and peers, they adopted self-destructive behaviour like banging their heads against a wall, which frightened other people. A few stories presented examples of good relationships with helpful peer groups in schools, who were friendly, played together and helped in studies. Promoting awareness among the school teachers by the CBR programme seemed to help in improving relationships with teachers and peers in the schools.

Difficulties related to activities of daily living

Some persons were not autonomous in their activities of daily living. Families did not know how to promote autonomy and this created stress in the family. CBR workers sometimes explained to families how to promote autonomy and they facilitated access to assistive devices. This was appreciated by the families. However, the families complained about lack of specialists and services that were usually located far away in cities and difficult to access because of lack of transport and financial resources.

Access to health services

The health services were not easily accessible. The staff of health services usually did not know anything about intellectual disabilities. They used inappropriate words like ‘mad’ or ‘idiot’ while talking to the families. Sometimes they refused to provide routine health care services suggesting the families to take persons with intellectual disabilities to specialized institutions in the cities. CBR workers had created some awareness among the health staff but it was not enough. CBR workers themselves did not have sufficient training about different kinds of intellectual disabilities.

In case of any illness, families usually provided home treatment. Only when the persons with intellectual disabilities were very ill, they were taken to traditional healers, or, less often, to health services and private doctors.

Access to education

In most life-stories, the schools were not willing to accept these children. Both school teachers and parents of other children were against the inclusion of children with intellectual disabilities. Often parents had to undertake repeated representations and discussions with school authorities to accept their children and let them continue to attend classes even when they were not very good at class work and exams. Sometimes the parents were accompanied by CBR workers. Persons with intellectual disabilities and their family members usually spoke of schools as important places for making friends and for social interaction, even if there were some episodes of abuse or discrimination by some peer groups.

Access to community rights

In many stories, community members created problems for persons with intellectual disabilities regarding their access to temples and common community areas, such as speaking in the panchayat (local village council) meetings and for voting in the local elections. Often, they advised families to not to bring the persons with intellectual disabilities in the common public areas. Sometimes CBR workers were able to help in resolving these problems by talking to community leaders and providing information, but occasionally this was not enough.

Participation in SHGs and DPOs

Many persons with intellectual disabilities were members of the village SHGs promoted by the CBR project. However, they rarely participated in the SHG meetings and usually a family member represented them. Very few persons with intellectual disabilities were represented in the sub-district and district level DPOs. There also, usually their family members participated in these meetings.

Difficulties in meeting other persons with intellectual disabilities

Many persons with intellectual disabilities and especially their family members cried while sharing their life stories, explaining that this was the first time they were talking about their problems in a public forum. They expressed their feelings of isolation and hopelessness. For them, SHGs and meetings with CBR workers were useful spaces to find information and access Government schemes, but they were not always able to make the persons with other disabilities, understand their social problems.

Benefits of participating in the residential meeting

During the feedback session, participants said that the meeting had provided different opportunities for sharing of experiences and information among themselves as well as from DPO members and CBR workers, both during the formal meeting sessions as well as during their free times and in the evenings. They had learned about different laws, schemes and opportunities related to intellectual disabilities, and how to access these.

At the end of the meeting, the participants expressed satisfaction regarding their participation and regarding the possibility of meeting other persons who were facing similar problems. Most persons had never met other persons with intellectual disabilities. Many said that it was the first time that they were asked to talk about their lives. Some of them said that they did not know about the different entitlements and government schemes and talking to other persons in the meeting had provided them with lot of useful information. Almost all participants said that they had come to the meeting with many doubts about just sitting together and talking, without receiving other services, however they had found it both interesting and useful. They also said that if similar meetings were repeated, they would like to participate again and they would advise other families to come to such meetings.

Discussion

The ER process facilitated people to share life stories in a peer group setting. This helped to make explicit the individual knowledge of living with intellectual disabilities, as well as to understand that they were not alone, rather there were others like them who were facing similar challenges and there could be ways to act collectively. By discussing the barriers faced and strategies to overcome those barriers, there was an attempt to promote thinking on use of existing laws and schemes in finding solutions, as well as to stimulate how to share this knowledge with others in the community. The building of shared knowledge about intellectual disabilities was important not just for wider community, but was equally important for CBR workers and DPOs who had, in spite of their goal of working with persons with different disabilities, limited knowledge and understanding about the issues faced by persons with intellectual disabilities.

All persons with disabilities face various kinds of barriers, however the negative attitudinal barriers faced by persons with intellectual disabilities seem to be particularly grave, much more severe compared to those faced by other groups of persons with disabilities, probably because these are associated with social stigma, discrimination and exclusion. Thus, the barriers identified and the peer sharing processes can be useful in building shared knowledge among other groups of persons who face social stigma and exclusion.

The residential meeting of persons with intellectual disabilities was difficult to organise. One of the barriers was the attitudes of persons with disabilities who were involved as researchers. They could not visualize persons with intellectual disabilities as persons capable of sharing their life stories in meaningful way. To some extent, this barrier was also shared by many CBR workers. At the community level, the SHG members and families of persons with disabilities also had similar attitudes. They could not understand why it was important for these persons to go to the meeting themselves and why family members could not represent them on their own. Families were worried about the reactions of their neighbours and other community persons that they would meet during the journeys. They felt that persons with intellectual disabilities will be difficult to manage outside their usual surroundings and will not be able to adjust to staying in a new place.

Although more than 90% of the meeting participants were defined by the CBR programme as persons with ‘mild’ intellectual disabilities, their education and employment backgrounds were an indicator of the numerous barriers surrounding their lives and limiting their opportunities of participation. The stories shared by these persons and their families in the meeting denoted the situation in a rural area where apart from the CBR programme, there were no other resources or institutions available to them. The nearest referral level institutions were in the cities like Bangalore and Mysore but accessing the services in the cities was not easy. Negative attitudes in families, communities and different institutions were the biggest barriers for persons with intellectual disabilities. These touched on all the different domains of life and limited the opportunities of participation of persons with intellectual disabilities in different life-activities. Even in the collective groups like SHGs and DPOs, where persons with disabilities join together to fight for their rights, the participation of persons with intellectual disabilities was difficult. Many of these difficulties were related to the attitudes and knowledge of other persons in the communities and persons with other disabilities. However, some of the difficulties were also related to persons with intellectual disabilities themselves, who found it difficult to sit in meetings and participate in discussions that they could not understand.

Limitations of the research

Persons with disabilities from local communities were the researchers and controlled all the different aspects of this research, including the preparation and analysis of the reports, which were prepared in the local language (Kannada). This facilitated wide participation and ownership of the research in the local communities. At the same time, it created difficulties for the sharing of the academic research findings. This paper is based on the English translation of the report prepared by the persons with disabilities who were researchers. Thus, the paper has the advantages and limitations of representing the views and analysis of persons who were also the subjects of the research and had limited skills as researchers. At the same time, the paper is limited by its focus on one specific research activity (sharing of life stories) and lacks an overview of the research process that had other components and was spread out over a period of two years. For example, the paper ignores the video-making process and the follow-up of the meeting discussions at the community level.

Additional insights

The report of this meeting was discussed with the CBR workers. They pointed out that their CBR training was very limited about specific issues related to intellectual disabilities. Thus, while they were able to promote general activities such as the access to disability certificates and other entitlements including assistive devices, they lacked the specific skills such as those for promoting autonomy in activities of daily living among persons with intellectual disabilities. CBR workers also expressed surprise at the frequent stories of violence that had come out in the sharing of life-stories. They said that while they knew about some persons who faced violence, they were not aware that it was so common. They proposed to play a more active role in future in promoting self-participation by persons with intellectual disabilities in SHGs and DPOs. Representatives of the local DPO who were involved as researchers in this meeting also expressed their own lack of understanding about the lives of the persons with intellectual disabilities and the kind of barriers they faced. They also proposed to play a more active role in future in promoting the participation of persons with intellectual disabilities in DPOs at different levels.

Sharing of life stories can be part of an empowerment process. Not just sharing of life-stories but also ‘just witnessing - really hearing, understanding and accepting without judgement - another's life story can be transforming’ (Birren 1996). Persons participating in the residential meeting expressed their satisfaction at sharing of their life experiences and at listening about lives of their peers. The limited time frame of the residential meeting is insufficient to understand if it contributed to a process of empowerment among the participants.

Conclusions

The life-stories of persons with intellectual disabilities can help us to understand the barriers they face and the difficulties of finding ways to overcome those barriers. The testimonies collected during this research showed that persons with intellectual disabilities face huge barriers, especially in terms of negative attitudes. Even for persons with ‘mild’ intellectual disabilities, the research showed that the barriers they face were pervasive, they touched on all the different domains of lives. It also showed that families with such persons require the support of different institutions, which were missing in the project area.

The research showed that emancipatory research approach based on sharing of life stories is feasible for persons with intellectual disabilities in the context of developing countries. It can provide rich details about the lives of the people, and the barriers they face every day. It also showed that the while CBR programme helped the persons with intellectual disabilities in different ways, the community workers need more understanding and skills in this area. Often CBR workers do not talk directly to persons with intellectual disabilities and presume that these persons will not be able to understand and respond. Similar ideas are shared by other persons with disabilities and their organisations. This research showed that such ideas may not be correct and that with the help of families, persons with intellectual disabilities can assume their own agency and share their ideas, desires and expectations. The task of changing negative attitudes in families, communities and institutions is extremely challenging. However, increasing the engagement with persons with intellectual disabilities and their families for understanding their difficulties can be a first step to raise awareness and to initiate a debate on how better support mechanisms can be developed.

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