

Research Article

'With Hope to Help Ourselves and Others': The Impact of Disabled People's Organisations on the Lives of Persons with Disability in Uttarakhand, North India

Michelle Leung, MD (1), Alexandra Devine, PHP, MPH (1), Lawrence Singh (2),
Teem-Wing Yip, FAFPHM, FACRRM, PHM, MBBS (1),
& Nathan Grills, PhD, MPH, MBBS (1,3)

(1) *The Nossal Institute for Global Health, Melbourne School for Population and Global Health, The University of Melbourne, Australia*

(2) *HOPE Project, Agnes Kunze Society, Dehradun, India*

(3) *Australia India Institute, The University of Melbourne, Australia
Melbourne, Australia and Dehradun, India*

Abstract: This study conducted in Uttarakhand, North India aims to contribute evidence on the effectiveness of Disabled People's Organisations in a low and middle-income context. Key domains reported by participants included: increased social connectedness, personal development, livelihood, improved sense of community, and participation within the family.

Keywords: Disabled People's Organisations; Persons with Disabilities; Inclusion

Background

Disability is a complex and evolving concept. The conceptualization of disability outlined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is perhaps the most salient and representative of persons with disabilities. It defines persons with disabilities as "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (United Nations, 2006, Art. 1).

The barriers mentioned in the Article 1 of the Convention on the Rights of Persons with Disabilities (CRPD) may include limited awareness of disability or negative attitudes within communities; inaccessible buildings or transport; lack of access to information in accessible formats; or policies that do not promote equal participation by persons with disabilities (United Nations, 2006).

Stemming from the disability rights movement in the 1970s, the rights-based approach to disability emphasizes the dignity of persons with disability and their right to enjoy life on an equal basis with others (GIZ GmbH & CBM, 2012). The rights-based approach to disability inclusion recognizes that persons with disabilities have the same rights as persons without disabilities within society, such as the right to basic health care, thus embodying a paradigm shift away from the previous social welfare response to disability (Kayess & French, 2008). Moreover, this approach supports the implementation of the CRPD as it empowers people to know about their rights and increases the capacity and accountability of individuals and institutions to address barriers to attaining these rights (GIZ GmbH & CBM,

2012). ‘Nothing about us without us,’ a negotiating slogan adopted by the International Disability Caucus, is the principle in which the CRPD represents continual partnering between the United Nations (UN) and persons with disabilities (Kayess & French, 2008). Disability-inclusive practices envisions that persons with disabilities can fully participate in all aspects of society and have the potential to significantly contribute to their families and communities (CBM Australia, 2012).

Disabled People’s Organisations are established by and for people with disabilities. At the board and membership levels, DPOs are controlled by a majority of persons with a disability (at least 51%) (PWDA, 2017). The role of DPOs is to provide persons with disabilities with a voice of their own, identify needs, express views on priorities, evaluate services and advocate change and public awareness (PWDA, 2017). As a key pillar in the response to global disability, DPOs act to promote participation and wellbeing through activities such as advocacy, service provision and social support.

Community-based rehabilitation (CBR) is a strategy developed by the World Health Organization (WHO) following the 1978 Declaration of Alma-Ata. The purpose is to strengthen DPOs and provide equal opportunity and social inclusion for all persons with disabilities. This strategy promotes collaboration between persons with disabilities, community leaders, and their families to ensure inclusion and participation of persons with disabilities (WHO, 2017). Thus, CBR highlights the importance of DPOs in promoting inclusion. CBR is visually represented by the CBR Matrix (WHO, 2010) and consists of five key components, including: health, education, livelihood, social and empowerment (see Figure 1).

Figure 1 Community-Based Rehabilitation Matrix (WHO, 2010)

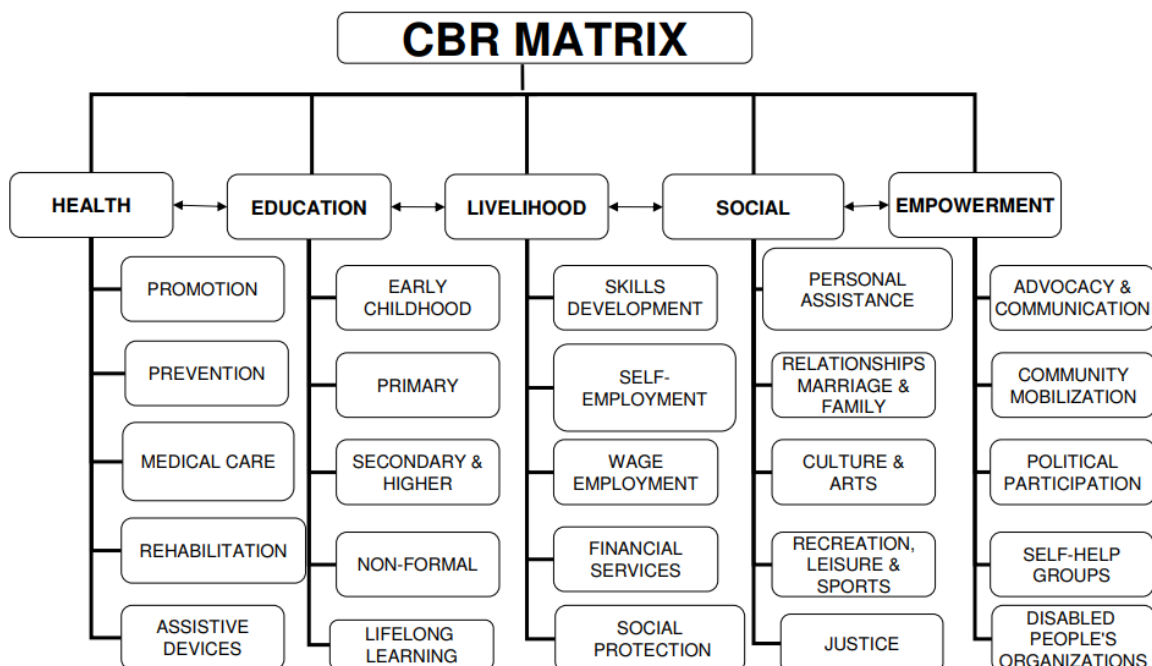


Image Description: The diagram of the ‘CBR Matrix’ includes five key components

representing health, education, livelihood, social and empowerment. Each key component includes sub-key components. The 'HEALTH' key component includes five sub-key components: promotion, prevention, medical care, rehabilitation, and assistive devices. The 'EDUCATION' key component includes five sub-key components: early childhood, primary, secondary & higher, non-formal, and lifelong learning. The 'LIVELIHOOD' key component includes five sub-key components: skills development, self-employment, wage employment, financial services, and social protection. The 'SOCIAL' key component includes five sub-key components: personal assistance, relationships marriage & family, culture & arts, recreation leisure & sports, and justice. The 'EMPOWERMENT' key component includes five sub-key components: advocacy & communication, community mobilization, political participation, self-help groups, and Disabled People's Organizations.

Since 2007, the Nossal Institute for Global Health has supported the development of a network of community health programs in North India, collectively referred to as the Community Health Global Network - Uttarakhand Cluster. The Uttarakhand Cluster has helped its members co-operate on activities such as health worker training, linking with the government health system and organizational strengthening. It has also collectively increased access to resources to improve the provision of community-level health and development services. Further, the Uttarakhand Cluster has developed a strong focus on improving the participation of persons with disabilities in their communities and promoting health and wellbeing. To support this, member organizations of the Uttarakhand Cluster have assisted persons with disabilities in forming networks and ultimately DPOs. The two DPOs studied here were formed as a result of people with disabilities coming together and realizing the need to work together. Samvedna non-governmental organization (NGO), representing the Uttarakhand Cluster, helped support the establishment of these nascent DPOs by facilitating training of the DPOs members in organizational management, their rights under the UNCRPD and advocacy options. The Samvedna NGO, henceforth referred to as the facilitating NGO, also organized learning visits to other DPOs and guided the DPOs through the complex process of applying for official DPOs registration. None of the facilitating NGO staff were members or leaders of the DPOs.

A previous process study found that the formalization of the DPOs was supported by initial efforts to promote community awareness of the rights of persons with disabilities, and financial and human resource support were provided through the Uttarakhand Cluster and local village leaders. Facilitating NGO staff worked with DPOs members to help them develop skills in effective group leadership; establishment of organizational practices and governance structures; advocacy and community awareness raising training; fundraising; and support to create more accessible environments. Local village leaders (Pradhan) provided the DPOs with a space to meet (Young, Grills, Reeve, Devine, & Singh, 2016). Networking and peer-exchanges between DPOs, whereby DPOs members of one group spent time with a more established DPOs to observe and learn from their practices. This enabled peer-led information sharing and fostered collaborative relationships between DPOs (Young et al., 2016).

Whereas the previous research has described the formation of DPOs, in this study we

aimed to contribute to the understanding of the effectiveness of DPOs in a low and middle-income context and the impact of DPOs on the lives of persons with disabilities and their families.

Methods

This qualitative study involved conducting semi-structured interviews and focus group discussions (FGD) - between February and March 2017 - across two study sites (of 15 DPOs sites) in Uttarakhand, North India. Ethics approval was received from the University of Melbourne Human Research Ethics Committee (HREC) and the local ethics committee of the Community Health Global Network (CHGN). In consultation with the facilitating NGO, the two sites selected were considered feasible for conducting the research, as well as, ensuring geographical representativeness and demographics of the study population. The first study site was located in the plains region of Dehradun District, with the second site located in the mountain region of Tehri Garhwal District (see Table 2 and 3 for demographics of the sites).

Table 2 *Demographics of the two DPO sites*

DPO study site	Location	Month/year of first group meeting	Number of DPO members at site	Age range	Location
1	Tehri Garhwal	January 2015	32	18-61	Samvedna Centre, Thatyur
2	Dehradun District	May 2015	44	18-70	Aarohi Sweet Shop, Badripur

Study Population

The study population were persons with disabilities currently participating in the DPOs, their family members and facilitating NGO staff (see Table 3 for demographics of study participants). The facilitating NGO staff were experienced in community mobilization and in working with people with disabilities.

Persons with disabilities were purposively sampled for interview in consultation with the facilitating NGO staff and DPOs members. The research team ensured a representative sample of age, gender, and type of disability, as well as, representation from people with different levels of involvement and inclusion in the DPOs activities. Family members that were recruited for interviews, were selected in consultation with persons with disabilities being interviewed. The NGO leaders helped identify the appropriate facilitating NGO staff to be interviewed. The sample consisted of twenty persons with disabilities currently participating in the DPOs, eight family members of persons with disabilities who have participated in the program, and 14 facilitating non-governmental organization staff. All participants were 18 years of age or older.

Table 3 *Demographics of Study Participants*

Type of interview	Total number of participants	Gender	Age	Type of disability
Tehri Garhwal District				
SSI (person with disability)	9	6 Male 3 Female	18–61	<ul style="list-style-type: none"> ● Physical impairment: 4 ● Sensory impairment: 2 ● Intellectual impairment: 1 ● Mixed impairment: 2
SSI (family of person with disability)	6	2 Male 4 Female	18–49	
FGD	8	4 Male 4 Female		
Dehradun District				
SSI (person with disability)	11	6 Male 5 Female	18–70	<ul style="list-style-type: none"> ● Physical impairment: 8 ● Sensory impairment: 0 ● Intellectual disability : 3 ● Multiple impairment: 0
SSI (family of person with disability)	6	2 Male 4 Female	19–53	
FGD	6	2 Male 4 Female	32–55	

Data Collection

The lead researcher conducted all semi-structured interviews and focus group discussions in English with the support of two Hindi-English translators. With the informed consent of all study participants, the semi-structured interviews and focus group discussions were recorded with an audio recording device. The duration of the semi-structured interviews was 20 minutes, and focus group discussions was one hour. The focus group discussions and semi-structured interviews were held at DPOs meeting sites or in participants' homes when accessibility to meeting sites were difficult.

The two Hindi translators received one-day of training, which involved familiarization with the process of informed consent, semi-structured interviews and focus group discussions question guides. Question guides were iteratively developed in consultation with the staff of the facilitating NGO in India and disability researchers in Australia. Interviews were transcribed in real time and translated into English. Written or verbal consent was obtained from all study participants.

Analysis

Inductive thematic analysis was used to analyze the data. In this ‘bottom up’ method, the patterns observed in the data were used to generate themes (Braun & Clarke, 2006).

This technique was chosen, as this coding approach is data driven, and avoided fitting data into analytic pre-conceptions or pre-existing coding frames, thus generated some unanticipated insights. Three research team members were involved in familiarization with the transcribed data, coding (organization of the data), identification of patterns, generation of themes, and finally discussion and reconciliation of any differences. From the patterns that emerged from the data, the research team generated 6 themes that were representative of the participants’ responses. Moreover, the barrier, enabler, outcome model, was utilized as an organizing framework for the analysis. This method involved sorting and grouping the recurring ideas of participants’ responses (from the semi-structured interviews and focus group discussions) into the categories of barriers, enablers and outcomes within each generated theme (see Table 1).

Results

Six themes characterized the impact of the DPOs on the lives of persons with disabilities and their families (see Table 1). These themes covered the domains of 1) social connectedness, 2) personal development, 3) participation within the community and family, 4) inclusion of previously excluded groups, 5) access to services, and 6) livelihoods. Study participants described barriers and enablers related to the overarching themes as experienced by persons with disabilities and their families.

The barriers identified by the participants were a mixture of barriers related to the broader lived experience of disabilities, as well as, barriers experienced by some participants in relation to their participation in the DPOs. Some of these barriers have been reduced through participation in the DPOs, while other barriers require ongoing action to address.

Table 1 *Summary of Overarching Themes Related to the Impact of DPOs*

Theme 1	DPOs created an opportunity for socialization and connectedness
Barriers	<ul style="list-style-type: none"> ● Negative attitudes of community towards persons with disabilities, thus leading to social isolation. ● Lack of support from community for persons with disabilities.
Enablers	<ul style="list-style-type: none"> ● Opportunity to develop friendships with other persons with disabilities and NGO staff through DPOs, thus leading to enhanced confidence that improves other relationships, such as with family. ● Mentoring of DPOs members by facilitating NGO staff. ● Social gatherings between neighboring villages.
Outcomes	<ul style="list-style-type: none"> ● Mutual understanding and peer support for individuals with disabilities, “I am not alone.”

	<ul style="list-style-type: none"> ● Peer support for family members of persons with disabilities.
Theme 2	DPOs empowered persons with disabilities
Barriers	<ul style="list-style-type: none"> ● Limited previous opportunities that promoted self-confidence and independence.
Enablers	<ul style="list-style-type: none"> ● Exposure visits to shopping malls. ● Support to develop skills that develop independence (e.g. self-care skills).
Outcomes	<ul style="list-style-type: none"> ● Increased self-confidence. ● Learning skills for increased independence. ● Increased skills for self-advocacy. ● Improved recognition of role and responsibility within the family.
Theme 3	DPOs increased involvement within the community and family
Barriers	<ul style="list-style-type: none"> ● Negative societal attitudes and stigma associated with disability. ● Lack of community support. ● Lack of family support. ● Expectation of DPOs as a service delivery.
Enablers	<ul style="list-style-type: none"> ● Attending DPOs meetings. ● Gaining knowledge at DPOs meetings.
Outcomes	<ul style="list-style-type: none"> ● Sharing knowledge with the village. ● Understanding about disability and the beneficial role of DPOs. ● Greater acceptance and respect from family and community.
Theme 4	DPOs promoted inclusion of previously excluded groups into the community
Barriers	<ul style="list-style-type: none"> ● Gender norms in some communities. ● Communication barriers. ● Attitudinal barriers. ● Venue accessibility for persons with disabilities. ● Geographical accessibility to villages for facilitating NGO staff.
Enablers	<ul style="list-style-type: none"> ● Building relationships with family members. ● Installation of ramps for wheelchair access. ● Female NGO staff traveling in pairs to remote villages.
Outcomes	<ul style="list-style-type: none"> ● Relationships between DPOs members and the facilitating NGO staff that is established on trust. ● Inclusion of previously excluded groups such as women. ● Persons with hearing impairments and intellectual disability remain excluded. ● Persons with disabilities in geographically isolated settings still encounter difficulty in attending DPOs meetings.
Theme 5	DPOs increased access to government services and resources
Barriers	<ul style="list-style-type: none"> ● Lack of awareness of persons with disabilities in the existence of services. ● Limited access to services.

Enablers	<ul style="list-style-type: none"> ● Facilitating NGO staff provided knowledge about services.
Outcomes	<ul style="list-style-type: none"> ● Increased usage of disability-specific services. ● Meeting material needs. ● Developing relationships with health professionals.
Theme 6	DPOs contributed to livelihoods of persons with disability
Barriers	<ul style="list-style-type: none"> ● DPOs meeting times interfering with work. ● Lack of opportunities for persons with disabilities to work.
Enablers	<ul style="list-style-type: none"> ● Income generating activities. ● Tailored meeting times to fit agricultural work schedule.
Outcomes	<ul style="list-style-type: none"> ● Increased access to income, savings, and jobs. ● Opportunity to work is not universal across DPOs sites.

Theme 1: DPOs Created an Opportunity for Socialization and Connectedness

Involvement in the DPOs provided persons with disabilities with opportunities to form social connections with other persons with disabilities and staff of the facilitating NGO. Prior to joining DPOs, persons with disabilities often experienced social isolation, and lack of support from the village and broader community. One DPOs member expressed, “[my] thinking has changed. I used to stay at home alone. There was no one like me. Now I come to the DPOs meeting, and was encouraged” (male with a physical disability, aged 30, Dehradun District).

After becoming involved in the DPOs, persons with disabilities were able to recognize that there were other persons with disabilities. Participants described the relief of discovering, often for the first time, that there were other persons with disabilities living in their communities who had shared similar circumstances and challenges. As a result, they no longer felt that they were alone and they felt a sense of connectedness with their peers. For example, one DPOs member commented, “Before joining DPO, I used to feel uncomfortable when going out. After joining DPO, I feel DPO members are my family” (female with an intellectual disability, aged 24, Dehradun District).

Facilitating NGO staff also highlighted that the DPOs increased the visibility of persons with disabilities in the community. Six out of the six NGO staff members from Dehradun district agreed that the increased visibility encouraged others to participate, “Seeing other persons with disability in DPO meetings motivates [other] persons with disability to attend” (facilitating NGO staff member, Dehradun District).

Family members also reported they found comfort and a sense of connectedness in the realization that there were other families in the community that has a family member with a disability. One father for example commented, “My son sits with other children with [a] disability. I feel good that my son isn’t the only child with disability and no longer feel sad” (father of DPOs participant with a physical disability, Tehri Garhwal).

Theme 2: DPOs Empowered Persons with Disability

Prior to joining the DPOs, participants described that their lives were negatively affected by anxiety and a lack of self-confidence. After joining the DPOs, many participants reported that they had experienced what can be described as personal growth. This included increased self-confidence, gaining independence, and improved capacity for self-advocacy. It was noted that DPOs members who were more frequently involved in DPOs activities were more likely to report on increased self-confidence and the feeling of empowerment.

Persons with disabilities and their family reported that activities organized through the DPOs, such as support to develop self-care skills and community outings, helped develop independence and fostered a sense of empowerment among persons with disabilities. As described by one family member, “She has learnt her signature and can go to the bank alone. [She] goes everywhere alone” (sister-in-law of DPO participant with a physical disability, Dehradun District). The self-confidence of persons with disabilities were also enhanced when four individuals from the Dehradun District mentioned they had positive interactions with other community members during DPOs community outings, “People in the mall respected us a lot” (female with a physical disability, aged 25, Dehradun District).

Increased self-confidence and empowerment gained through participating in the DPOs enabled participants to engage in other aspects of their communities, including the area of self-advocacy. This was most pertinently described by a participant in his newfound confidence and desire for taking ownership in advocating for persons with disabilities and leaving a legacy:

Initially, I didn't talk to neighbors. Now I can even talk to Chief Minister of Uttarakhand. [I am] more confident...I thought, what will we as persons with disability do? Used to wait for time to pass. Now, I think we have to do something, so the world can remember us (male with a physical disability, aged 30, Dehradun District).

As highlighted by the following quote, in some cases, the confidence gained through the participation in the DPOs had a profound impact on the lives of persons with disabilities, “After joining DPOs, I have confidence, [I] can do. I started a business, got married, have daughter” (male with a physical disability, aged 25, Dehradun District).

Further, not only did the independence of persons with disabilities improve, but it also improved the families' confidence in the capacity of their family members with a disability to be independent and participate in their communities, “Before joining DPOs, my sister did not clean herself, not dress herself. After joining DPOs, she has learnt independent care skills. In preparation for attending DPOs meetings, she dresses herself, takes bath” (sister of DPOs participant with an intellectual disability, Tehri Garhwal).

Theme 3: DPOs Increased Involvement within the Family and Community

Prior to the presence of DPOs, persons with disabilities reported there was limited

understanding of disability within their communities and that they would often experience stigma and discrimination. This resulted in persons with disabilities remaining isolated within their homes. Facilitating NGO staff also highlighted that during the process of formalizing the DPOs, there was resistance from families and other community members to the idea of establishing DPOs and supporting the participation of persons with disabilities. For example:

Family members of persons with disability were unwelcoming and denied that PWD needed help. [They asked] what can you do for my family?... We had to explain that the motive for joining DPOs is to gain rights, join community, gain resources and knowledge about government schemes (facilitating NGO staff member, Tehri Garhwal).

Participants reported that DPOs continue to promote positive attitudes towards disabilities within their communities, this includes improved understanding within the community and support from families with disability members to participate in DPOs. Additionally, the DPOs provide a platform for persons with disabilities to learn about their own rights, as well as, acquire health promotion information. DPOs participants highlighted that they are now confident to share the knowledge they have learned with their communities. This demonstration of knowledge and confidence has further shifted the mindset of the community, with family members interviewed highlighting this as a positive impact. The initial skeptical attitude adopted by the village regarding the utility of the DPOs was reversed when the village could see positive change in the lives of persons with disabilities due to their involvement in the DPOs, “Before joining DPO, villagers and family used to tease my son, and didn’t call my son by name. Now the village and my family call my son by name” (father of DPOs participant with a physical disability, Tehri Garhwal).

“Initially, [the] village was cynical about what DPO could do. But now [the village] can see change in persons with disability, [so they are] no longer cynical” (mother of DPOs participant with an intellectual disability, Dehradun District).

As a result of the village and family members developing an understanding about disability and the beneficial role of DPOs, persons with disabilities reported they were now more likely to be treated with acceptance and respect within their families and the wider community. As described by one DPOs participant, “[the] village used to make fun of PWD, they didn’t ask PWD, ‘How are you?’ [the] village now respects PWD and accepts them as equals” (female with a physical disability, aged 40, Tehri Garhwal).

Theme 4: DPOs Promoted Inclusion of Previously Excluded Groups

During the early stages of the establishment of DPOs, facilitating NGO staff reported that they encountered difficulty in including some persons with disabilities. In particular, some family and community members were resistant to the inclusion of persons with disabilities from the local Muslim communities; persons who are Deaf or hard of hearing or with other communication difficulties; and persons with an intellectual disability. Some of these families and community members acted as gatekeepers and barriers to inclusion.

In the plains region of Dehradun District, all facilitating NGO staff participating in the focus group discussion (FGD) interviews described the difficulty of engaging the Muslim community. For example, “Initially, when facilitating NGO staff approached the homes of Muslim persons with disabilities, the Muslim males rejected the female staff. After being rejected, the staff members expressed feelings of anxiety and nervousness” (facilitating NGO staff member, Dehradun District). Facilitating NGO staff described the importance of gradually building the trust with the Muslim community and family members of persons with disabilities in order to gain their support to encourage their family members to participate in the DPOs.

Facilitating NGO staff also described ongoing efforts to develop relationships with persons with an intellectual disability and their families. While this was reported to have improved the participation of some persons with an intellectual disability within the DPOs, facilitating NGO staff acknowledged this participation is still reliant on the support of family members and/or support persons, “It is difficult to communicate with persons with intellectual disability if they are not with their caregiver or family member” (facilitating NGO staff member, Tehri Garhwal). The inclusion of persons who are Deaf or hard of hearing was reported to be prevented by the lack of the use of sign language by other people who are Deaf or hard of hearing, facilitating NGO staff, and the broader community.

All facilitating NGO staff commented that during the early stages of the DPOs formation process, physical accessibility was a major barrier to participation of persons with disabilities. Difficulty in the physical accessibility of the surrounding areas also affected both persons with disabilities traveling to DPOs meeting places, and staff of the facilitating NGO traveling to the homes of persons with disabilities. Since becoming aware of barriers in the accessibility of DPOs meeting sites, participants reported that DPOs have been collaborating with the staff of the facilitating NGO to try and improve the accessibility of meeting spaces, for example through the construction of ramps. However, persons with disabilities in geographically isolated villages still encountered difficulty in attending DPOs meetings.

Theme 5: DPOs Increased Access to Services and Resources

Before the formalization of the DPOs, persons with disabilities reportedly experienced very limited access to disability-specific and general health services. Through participation in the DPOs and the support of facilitating NGO staff, persons with disabilities and their families reported learning about government programs, such as the disability certificate which enables a person to receive a pension. Facilitating NGO staff were reported to have assisted persons with disabilities to register for these available entitlements. As such, one DPOs member remarked that, “after joining DPOs, problems were sorted, including disability certificate, pension” (male with a physical disability, aged 28, Tehri Garhwal).

DPOs members, often with the help of facilitating NGO staff, accessed other health care services including acquiring hearing aids, leg prostheses and wheelchairs. One DPOs member commented that through the DPOs, he had developed relationships with health professionals, including doctors and physiotherapists, who were then able to promote the

health seeking behavior of DPOs members. Examples were also shared of DPOs members working together to mobilize help for material needs of their members, “DPO organized the repairing [of] the family house and railing. To prevent falling when she has a seizure. This convinced her to join the DPO” (sister of DPOs participant with a physical disability, Tehri Garhwal).

Theme 6: DPOs Contributed to Livelihoods of Persons with Disabilities

Some DPOs were reported to have had a focus on income generating activities for their members. For example, “We collect monthly money for savings to deposit at bank to help other members” (female with a physical disability, aged 40, Tehri Garhwal). Similarly, as highlighted by another participant, “[We have] learned candle making, organic rubbish composting, paper earrings, apron making” (female with a physical disability, aged 25, Dehradun District). For some participants, this has led to access to some income, savings and skills for acquiring a job.

However, the opportunity to work was not universal across both DPOs sites. Whereas in the mountainous region of Tehri Garhwal, many persons with disabilities were reported to be involved in agriculture work, opportunities for agricultural livelihoods or other work was reported to be limited in the plain districts of Dehradun. Participants in these areas reported they were disappointed that their participation in the DPOs had not improved access to more livelihood opportunities for persons with disabilities. One person with a disability reported for example, “DPO has given me hope to help ourselves and others, but I have not seen any changes. I would like to see changes, since disability is a barrier to work. Disability prevents work. I want to see us do our own work” (male with a physical disability, aged 42, Dehradun District).

Discussion

This study demonstrated that participation in DPOs can have a positive impact on the lives of persons with disabilities and their families. Key areas where impact was found included: social connectedness, personal development, livelihood, community, and participation within the family.

The functioning of the DPOs evaluated in this study was supported by the framework presented by the CRPD, particularly the convention’s role in detailing the rights of persons with disabilities and setting a code of implementation. We found evidence that DPOs have contributed or are contributing to Article 8 through awareness raising; Article 25 through access to health; Article 27 through work and employment; Article 30 through the participation of cultural, recreation and leisure (United Nations, 2006).

The beneficial outcomes of DPOs in this study had effects across the five pillars of the WHO CBR Matrix, particularly in advancing health, empowerment, and social inclusion (WHO, 2010, 2017). This study showed that the activities of the DPOs were beginning to address the major objectives of the CBR, including; 1) ensuring that persons with disabilities

maximize their physical and mental abilities, thus becoming active contributors to the community; and 2) activating communities to promote and protect the human rights of persons with disabilities through changes within the community, for example, by removing barriers to participation. This was achieved through the combined efforts of persons with disabilities, their family and facilitating NGO staff.

Literature supporting that DPOs can improve participation of persons with disabilities in the community can be found (Young et al., 2016). In a study in India, it was similarly observed that self-help groups were an avenue for persons with disabilities to emerge from social isolation and engage in collective development and welfare (Kumaran, 2011). In addition, there were findings that DPOs challenged negative societal attitudes, resulting in greater acceptance of persons with disabilities in the village. This suggests that social connectedness of persons with disabilities with the broader community is beginning to occur.

Participating in activities conducted by facilitating NGO staff, included learning self-care skills and exposure through visits to a local mall. This enabled persons with disabilities to acquire skills and increased their self-confidence. The experience of empowerment, via participation, is consistent with other studies involving individuals with psycho-social disability in a low- and middle-income context (Carroll et al., 2016; Dhungana & Kusakabe, 2010).

Similar to what has been described in a study conducted in Nepal (Morrison et al., 2015), the DPOs in this study enabled persons with disabilities to experience greater acceptance from their family and greater engagement with their community. Participation in DPOs enabled information sharing about disabilities, which challenged and re-oriented previous negative attitudes. Moreover, there was evidence that groups of individuals, such as persons with an intellectual disability, who were previously excluded from participating in DPOs, but are now beginning to be included in the DPOs. These previously excluded groups not only included persons with an intellectual disability, but individuals from the Muslim community. Staff of the facilitating NGO reported that greater inclusion has been achieved due to DPO's addressing barriers to participation. Consistent efforts from facilitating NGO staff had reached out to previously excluded groups and their family members, which resulted in the DPOs gaining a greater understanding of the needs of these previously excluded groups. These needs included understanding the most effective way of communicating, building trust and affirming DPOs as an accessible space for all persons with disabilities (Polu & Nelson, 2015).

Our study found that DPOs enabled greater access to health and disability-specific services, consistent with the experiences of DPOs in other countries, for example Brazil (Deepak et al., 2013). During DPOs meetings, facilitating NGO staff informed DPOs members and assisted access to these services, including accessing disability pensions and mobility aids. Due to their tangible nature, access to health and disability-specific services was reported by many DPOs members as motivation for joining the DPOs. Upon participating in the DPOs, persons with disabilities then realized that service provision was not the only

role of DPOs, and utilized the DPOs for activities such as advocacy and social inclusion.

The priority of income generation was a strongly voiced finding in this study. Our study showed that DPOs play a critical role in providing opportunities for persons with disabilities to improve their livelihood. By providing a supportive space, DPOs enabled persons with disabilities to engage and cooperate with peers in the common goal of undertaking income generating activities. Opportunities for improving livelihood were not uniform across the two DPOs sites. DPOs members in the mountain region were typically engaged in agricultural work; however, several male DPOs members in the plains desired to work but felt they had no means to achieve this objective. They expressed that DPOs should be doing more to provide for this particular unmet need. Although the purpose of DPOs is to promote participation and wellbeing, it does not always translate into providing avenues for employment. A study conducted in India found that self-help groups had a vital role in facilitating persons with disabilities to work together for their collective welfare and livelihood (Morrison et al., 2015).

The barriers encountered by the DPOs in this study are acknowledged in literature. For example, in a study conducted in Bhalki, India, physical inaccessibility to venues is noted as a major barrier to attendance of persons with disabilities at DPOs meetings (Deepak et al., 2013). In our study, we found that while venue accessibility can be improved by DPOs, it is difficult to improve the accessibility to geographically isolated villages.

Lack of family and community support is commonly recognized as a significant barrier hindering persons with disabilities from participating in DPOs. As highlighted by a study in rural Nepal, we found that DPOs working alongside families to raise awareness about the benefits of DPOs attendance and participation addressed this barrier (Morrison et al., 2015).

Overall, the findings were consistent between the two DPOs sites. However, some differences existed. It was observed that the DPOs located within the plains region of Dehradun had members who were more motivated to participate in self-advocacy and in income-generating activities – some willing to take ownership of roles (e.g. President, Secretary, Treasurer) within the DPOs itself. This might be explained by the greater amount of time availability to actively engage in DPOs activities in plains populations as compared with DPOs members in the mountain region, who were often restricted by agricultural work commitments.

Difficulty in physically accessing DPOs venues may also be a contributing factor to the level of participation of persons with disabilities in DPOs activities. Moreover, education levels of DPOs members in the mountain region were generally lower than DPOs members in the plains region (see Table 3 for demographics of study participants), which may partly explain the difference in participation between the two contexts. This observation is consistent with the findings of a study in rural Nepal that described that some participants attributed their lack of education to difficulty in interacting and engaging in groups (Morrison et al., 2015).

Next Steps for DPOs, the Uttarakhand Cluster and Broader Community: Implications for Scaling-up DPOs

To improve participation of persons with disabilities in the DPOs, and ultimately enable persons with disabilities to realize their rights to participate in society on an equal basis with others, DPOs should continually address the barriers identified through this study. To enable greater inclusion of persons who are Deaf or hard of hearing and persons with an intellectual disability. In addition, DPOs should continue activities that promote inclusion of marginalized groups of persons with disabilities in society. These activities could include facilitating NGO staff training of DPOs members in effective communication with individuals who are Deaf or hard of hearing and persons with an intellectual disability. Facilitating NGO staff members therefore need to build their own capacity to work with persons with an intellectual disability.

DPOs should increase physical accessibility of DPOs meeting venues for persons with a physical disability, particularly for individuals from geographically isolated settings. A possible strategy is to alternate DPOs meeting venues to allow all DPOs members an opportunity to meet closer to their homes. This could be arranged with the help of the local village leadership and in discussion with DPOs members and facilitating NGO staff.

To address DPOs members desiring more opportunities to improve their livelihood, DPOs should continue to work with facilitating NGO staff to better understand the barriers to livelihood opportunities for persons with disabilities in the plains districts. Subsequently, local solutions should be developed to address barriers to livelihoods. Further research could explore how DPOs can support DPOs members in opportunities for income generation.

As a result of the positive findings from this study, which showed that activities such as information sharing and exposure through visits to malls were effective ways for persons with disabilities to engage with their community, we recommend that DPOs should continue to encourage persons with disabilities to participate in self-advocacy activities.

Limitations

Ideally, if the research team would have included persons with disabilities, this may have yielded more insightful and in-depth responses. A selection bias may have occurred, as field managers helped researchers recruit participants. There may have been a tendency for the inclusion of participants who were more confident and had direct positive experiences at the DPOs. The nature of FGDs may not facilitate equal contributions from all participants.

It is difficult to know how far these findings could be generalized. Even within our study, there were differences between the two study sites. However, our findings were largely consistent with findings from other studies on the effect of DPOs. Yet given the limited published evidence on the effect of DPOs, and given their widespread use in disability and development, it is imperative that other research is done to formally assess the impact of DPOs in alternative contexts.

The findings in this study were predominantly positive about the benefits of involvement in the DPOs. However, due to the power differential from the researchers' socioeconomic, cultural and educational backgrounds, participants may have felt the need to please the interviewer and give the 'right answers'. On the other hand, common themes of areas of impact emerged and they were supported by multiple participants from different geographical areas.

Conclusion

The study of the DPOs in Uttarakhand, North India determined that participation in DPOs had a positive impact on the lives of persons with disabilities, particularly for promoting social connectedness, personal development and livelihood. While participation in DPOs provides many benefits to persons with disabilities, many individuals still prioritize work as a core objective and an unmet need in the opportunities provided by DPOs. Many findings from this study were similarly described elsewhere in the literature, suggesting the findings might have currency when applied to other LMIC contexts. Further research may explore how DPOs can continue to better include individuals with hearing impairments and intellectual disability.

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Declaration of interest statement

The authors report no conflicts of interest.

Michelle Leung, MD, is a medical resident at Eastern Health, and was a MD student at the University of Melbourne, Melbourne School of Population and Global Health.

Alexandra Devine, PHP, MPH, is the Senior Research Officer, Disability Inclusive Development at the University of Melbourne, Melbourne, School for Population and Global Health, Nossal Institute for Global Health.

Lawrence Singh, is the Managing Direct at the Agnes Kunze Society, HOPE Project in Dehradun, India.

Teem-Wing Yip, FAFPHM, FACRRM, MPH, MBBS, is a Public Health Physician, Public Health at the University of Melbourne, Melbourne, School for Population and Global Health, Nossal Institute for Global Health.

Nathan Grills, PhD, MPH, MBBS, is an Associate Professor, Public Health Physician, and NHMRC Postdoctoral Fellow, Public Health at the University of Melbourne, Melbourne School for Population and Global Health, Nossal Institute for Global Health, and the Australia India Institute.

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