

Methodological Approaches to Researching Organisations of Persons with Disabilities: a Case Study from Uttarakhand, North India

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ABSTRACT

Purpose: *Organisations of Persons with Disabilities (OPDs) are promoted to encourage the inclusion of persons with disabilities in development programmes. However, there is little peer-reviewed literature on the effectiveness of OPDs in low and middle-income countries.*

This Case Study in Uttarakhand State of North India, aimed to explore the methodological approaches used to understand and evaluate the formation and function of OPDs.

Method: *The Nossal Institute of Global Health, Australia, partnered with the Uttarakhand Cluster (an NGO in India) to facilitate the development of Organisations of Persons with Disabilities. Five research studies were undertaken between 2014 and 2018 to understand their formation and function. The current Case Study has focused on these 5 studies, examined the qualitative and quantitative methodological approaches that were used in each study, summarised their findings, and analysed the advantages and limitations of the methodologies used in the context of the formation and function of OPDs.*

Results: *The methodologies used included: Thematic analysis; Realist Evaluation; Participatory Action Research using Videovoice; Social Network Analysis; and a Cluster Randomised Trial. By examining the 5 selected studies, rather than drawing conclusions from any individual methodology, this Case Study derived a better understanding of OPDs in Uttarakhand. OPDs were seen to have had positive impacts across a variety of domains.*

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Conclusion and Implications: *The Case Study showed the value of multiple and mixed methods approaches to study complex phenomena such as the formation and function of OPDs. It helped in understanding the mechanisms for OPD impact.*

Key words: *DPO, OPD, Organisations of People with Disability, India*

INTRODUCTION

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) highlights the importance of persons with disability being central to all aspects of decision-making that affect them (United Nations, 2006; United Nations General Assembly, 2016). This is embodied by the motto of the disability rights movement “nothing about us without us” (Callus & Camilleri Zahra, 2017). Perhaps the central mechanism advocated to achieve the involvement and participation of persons with disability has been the formation of Organisations of Persons with Disabilities or OPDs (United Nations, 2006; United Nations General Assembly, 2016). Disabled People’s Organisations or DPOs was the term used at the time of the initial studies and therefore the term is used in reference to these studies.

Organisations of Persons with Disabilities are formal groups composed of, led, and controlled by persons with disabilities and those with lived experience of disability such as families or caregivers (Deepak et al., 2013; United Nations General Assembly, 2016). The functions and characteristics of OPDs can vary, but key elements include advocacy, providing a “voice” for people with disabilities, evaluating service and systems, expressing priorities and promoting public awareness (Disabled People’s Organisations Australia, n.d).

Although disability programmes are typically required to work with OPDs, and despite being considered a fundamental right for people with disabilities (United Nations, 2006; World Health Organisation, 2011), there has been little published evidence regarding their actual impact. Similarly, methodological approaches to researching OPD functions and their impact have not been well characterised.

A literature review undertaken in 2016 by Young et al (Young et al., 2016) examined peer-reviewed literature that studied the roles, functions and impacts of Organisations of Persons with Disabilities. Eleven studies that were identified for inclusion consisted of eight qualitative studies (Armstrong, 1993; Cobley, 2013; Deepak et al., 2013; Dhungana & Kusakabe, 2010; Griffiths et al., 2009; Hemingway

& Priestley, 2006; Kleintjes et al., 2013; Miles et al., 2012), two mixed methods studies (Polu et al., 2015; Stewart & Bhagwanjee, 1999), and one quantitative cohort study (Kumaran, 2011) - the quality of which was described as poor. The qualitative studies were of variable quality. The CASP Qualitative research checklist classified 3 studies as 'High quality', 4 studies as 'Medium quality', and 3 studies as 'Low quality' (Young et al., 2016). Demographic information was minimally presented, making it difficult to judge the generalisability. The authors undertook thematic analysis and presented their findings under three themes: 1) participation (awareness of rights, increased confidence for participation, involvement in advocacy and awareness-raising activities); 2) the development of connections (creation of networks, and improved social connections); and 3) self-development (improved access to orthopaedic devices, medical and orthopaedic services, housing, training and education, microfinance).

This literature review by Young et al is the only published review of studies pertaining to the function and effectiveness of OPDs. Poor reporting and the variable levels of quality of the studies warrant further research to explore the identified functions of OPDs and their impact. In addition, each study was related to different OPDs, with consequent inability to triangulate research on any particular OPD.

Since 2007, the Nossal Institute for Global Health has supported the development of a network of community health programmes based in the northern Indian State of Uttarakhand. The Community Health Global Network, "Uttarakhand Cluster" (CHGN-UKC), now consists of fifty member organisations which cover a catchment area of more than 2 million people. In 2009, the Cluster identified that persons with disabilities were often excluded from health and development programmes. In response, the Cluster decided to focus on disability, both in terms of awareness-raising and the promotion of disability inclusive development (Grills et al., 2016).

One aspect of the work undertaken by the Uttarakhand Cluster was facilitating the development of Organisations of Persons with Disabilities, as well as researching their function and impact. Since 2015, the Nossal Institute for Global Health in partnership with CBM and the Uttarakhand Cluster have utilised five different methodological approaches to explore the formation and function of the Organisations of Persons with Disabilities that they helped facilitate.

Objective

This Case Study aimed to build upon the existing literature by exploring the methodological approaches used to understand and evaluate the formation and function of these OPDs in Uttarakhand, over a four-year period. It summarised the findings from the 5 studies and examined the advantages and limitations of the methodologies used, in order to provide an in-depth exploration of Organisations of Persons with Disabilities and the utility of methodologies to research them.

METHOD

Setting

Between 2015 and 2019, the CHGN Uttarakhand Cluster was involved in facilitating OPD formation. Uttarakhand state, located in the Himalayan foothills of North India, is a predominantly rural state with high levels of poverty. It has a population of 11 million people, 6.8% of whom have disability (Grills et al., 2017). This involved identifying people with disability using the Rapid Assessment of Disability tool (RAD), undertaking community sensitisation, conducting training in the formalities of running a registered group, assisting in the formal registration process, and helping with various activities such as clinics and community awareness meetings.

Five studies were undertaken at different points over the course of the 5-year process of OPD formation and support for OPD activities. These studies were undertaken by the Nossal Institute for Global Health, with financial support from CBM India, and in partnership with the Uttarakhand Cluster. Each study investigated, at different time points, aspects of formation and function of Disabled People's Organisations in Uttarakhand.

This Case Study collates and analyses the findings and methodologies from these 5 studies to tell the coherent and interesting story of the Uttarakhand OPDs.

Study Design

For each of these studies the methodology and findings were summarised. The summary provided key study and methodological attributes, including items such as aspects of the OPD studied (formation, function and impact), location, sample and sampling technique, outcome measures and tools utilised.

The 5 studies were analysed to compile the key findings related to OPD formation and function, and the results were descriptively tabulated detailing the study type, timeframe, research questions, and methodology used.

Where indicated, the wider literature was consulted to provide an overview of the methodological approach, including its known advantages and limitations. Consequently, the strengths and limitations of using that approach were analysed within the context of exploring the formation and function of Organisations of Persons with Disabilities in Uttarakhand State.

The discussion brings together some of the key findings about the combination of methods utilised and the overall findings from the Case Study of OPD formation in Uttarakhand.

RESULTS

Table 1: Summary of the Five Studies and the Methodologies Utilised

| Authors | Time frame | Study Design | Research Question/s | Methods |
|---|-------------|--------------------------------|--|---|
| Leung M et al. '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 | 2017 | Qualitative Thematic Analysis | (1) To understand the impact of OPDs on the lives of persons with disabilities and their families (2) To understand the enablers and barriers to the involvement of persons with disability within OPDs | Semi-structured interviews, Focus Group Discussions, local translators (trained), transcription, translation into English, inductive thematic analysis |
| Young R et al. A realist evaluation of the formation of groups of people with disabilities in North India | 2015 - 2016 | Qualitative Realist Evaluation | Why and how different factors affect the development and operation of Disabled People's Groups | Context- mechanism-outcome configurations developed, tested and refined using 5 case studies; also Focus Group Discussions, Semi-structured interviews, field observations, review of key documents |

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|---|-------------|--|--|---|
| Montgomery J et al. Disabled People's Organisations grow social connectedness for persons with disability: Evidence from South Asia | 2018 | Mixed Methods Social Network Analysis | What impact can participation in Organisations of Persons with Disabilities have, on the social networks of persons with disability? | Mixed Methods: Network mapping survey before and after joining OPD, Focus Group Discussions (participants and staff), thematic analysis of Focus Group Discussions |
| Butcher N et al. Videovoice Study Finds Transactional Benefits and Personal Impact of DPO Membership | 2019 | Qualitative Participatory Action Research - Videovoice | How and when do OPDs have an impact on their members? | Training followed by participant production of narrated 2- minute video product, Semi-structured interviews, Focus Group Discussions |
| Grills N et al. Disabled People's Organisations increase access to services and improve well-being: evidence from a cluster randomised trial in North India. | 2014 - 2018 | Cluster Randomised Intervention Trial | Do OPDs improve the access to services and well-being of their participants? | Intervention group facilitated to form OPDs, non-intervention group continued with normal disability programmes, random allocation, baseline and end-line surveys using RAD survey tool |

Table 2: Summary of the Findings from the Five Studies

| Study | Findings |
|--|--|
| Leung M et al '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 | Positive impacts of OPDs were collated under six key themes: Social connectedness: with other persons with disability and NGO staff, also for family members of persons with disabilities. Empowerment of persons with disability: increased self-confidence, increased independence, improved capacity for self-advocacy. Participation within community: OPDs promoted positive attitudes towards persons with disability, increased knowledge sharing by persons with disability with community, increased community awareness and increased respect from family/community. |

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|---|---|
| | <p>Promotion of the inclusion of previously excluded groups: inclusion of women and other groups although some people remained excluded, including Muslims (NGO staff needed to gain trust of Muslim community), persons with hearing disabilities (lack of use of sign language by persons with disability and NGO staff and broader community) and persons with intellectual disability (difficult to communicate with persons with disability if family or carer was not present).</p> <p>Access to services: difficulty for persons with disability getting to meeting places (transportation) and accessibility issues at OPD venues. OPDs improved access to government programmes – help with accessing financial support such as pensions, improved access to assistive devices (eg. wheelchairs, hearing aids, etc.).</p> <p>Livelihoods: some OPDs focussed on income-generating activities, such as agricultural work in mountain areas.</p> |
| <p>Young R et al.</p> <p>A realist evaluation of the formation of groups of people with disabilities in North India</p> | <p>Factors enabling formation and functioning of OPDs were grouped under three themes:</p> <p>External Supports: group members valued NGO initial information sharing and financial support; NGO staff engaged on an equal basis, emergence of NGO champions to encourage those with disabilities and their families to join OPD, networks with other OPDs led to peer-led information and knowledge sharing and improvement in confidence of OPD members and acceleration of OPD formation.</p> <p>Community and physical environment: increased member confidence influenced community perceptions; village leader support important, formation of OPDs led to increased village leader interest in disability issues, physical and environmental barriers limited involvement, and reliance on the NGO and family to support group involvement.</p> <p>Group composition: promotion of equality of socially and culturally diverse members, i.e., different cultures, religions and castes able to exist in the same OPD. Often those with profound disability were more excluded. Parents played a role representing them.</p> |
| <p>Montgomery J et al.</p> <p>Disabled People’s Organisations grow social connectedness for persons with disability: Evidence from South Asia</p> | <p>OPDs increased the breadth of social networks for participants as well as increased the interconnectedness between participants.</p> <p>This increased social connectedness led to improved self-esteem, social acceptance, increased access to services (financial, medical care and assistive devices), opportunities for friendship and possibilities of collective advocacy, access to employment opportunities.</p> <p>Negative impacts included time burden in relation to family and work.</p> |

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|---|---|
| <p>Butcher N et al.</p> <p>DPO membership has immediate transactional benefits as well as personal impact</p> | <p>Information and knowledge gain: joining OPDs led to information and knowledge gain and positive emotions.</p> <p>Material benefits: access to goods, government pensions, assistive devices, housing improvements.</p> <p>Skills: direct (access to skills training) or indirect (education opportunities).</p> <p>Personal: awareness, confidence and improved self-image and motivation (to be domestically, socially or vocationally active).</p> <p>Social: getting to know others, creation of social networks.</p> <p>Note: social and personal were the most discussed topics (50% of dialogue), followed by information/education and material benefits (40% of dialogue), and then skills and other (10% of dialogue).</p> |
| <p>Grills N et al.</p> <p>Disabled People's Organisations increase access to services and improve well-being: evidence from a cluster randomised trial in North India</p> | <p>Compared to controls - OPD formation led to significant improvement in:</p> <ul style="list-style-type: none"> • persons with disability participating in community consultations, social activities and OPDS; • improved access to toilet facilities, rehabilitation, and Government social welfare services; • improvement in having their opinions heard and being able to make friends; • Other improvements noted were not statistically significant. |

SUMMARY AND ANALYSIS OF THE METHODOLOGIES USED IN THE FIVE INCLUDED STUDIES

Study 1. 'With hope to help ourselves and others': The impact of Organisations of Persons with Disabilities on the lives of persons with disability in Uttarakhand, North India (Leung et al., 2019)

Study methodology: Qualitative

Aspects of OPD studied: Impact

Detailed Methodology

This study utilised Semi-Structured Interviews (SSIs) and Focus Group Discussions (FGDs) with 20 people with disability who were members of an Organisation of People with Disability and 8 of their family members. The researchers also

interviewed the 14 Uttarakhand Cluster staff who were facilitating the formation of OPDs in Uttarakhand. People with disabilities were purposively sampled, and the sample was representative across age, gender, disability type and different levels of OPD involvement. Family members were selected in consultation with the people with disability who were interviewed.

There was one day of training with the translators. Following this, SSIs and FGDs were conducted in English, with the Hindi-English translators, and recorded and analysed using inductive thematic analysis.

Advantages of a Qualitative Approach in this context

This study used a qualitative approach to explore the **impacts** that OPDs had on the participating persons with disability and their families. These were described under 6 themes (see summary of themes in Table 2) which included a description of the enablers and barriers to achieving the described impact. Using this qualitative approach provided in-depth information that would have been difficult to elicit with a quantitative approach. The exploration of enablers and barriers allowed recognition of some of the features that could enhance or jeopardise the ability to achieve the identified impacts.

Utilising translators for the interviews provided the opportunity for persons with disabilities to voice their thoughts in their own language and meant that English language literacy was not an impediment to their inclusion. The small number of participants simplified the logistics and allowed in-depth exploration with each participant.

Identifying themes by using an inductive approach during analysis allowed the researcher to construct themes that may not have been identified in a deductive approach using pre-established hypotheses about the data (Bhattacharya, 2017).

Limitations of a Qualitative Approach in this context

The small sample size as well as participants being members of only two OPDs within a defined geographical area may affect generalisability. To some extent this was addressed by ensuring there was demographic representation from the local area. However, to be generalisable, the impacts identified from a study of this nature would need to be correlated with those found elsewhere.

Using traditional semi-structured interviewing can exclude those with more severe disability, intellectual disability or communication disabilities.

The synthesis of the data from three distinct groups (persons with disability, family members and NGO field staff) into a single group of themes made it difficult to disaggregate differences between groups.

Study 2. A realist evaluation of the formation of groups of people with disabilities in North India (Young R et al., 2016) – A realist evaluation approach

Study methodology: Qualitative, Realist Evaluation, 5 Case Studies

Aspects of OPD studied: Formation and Function

Detailed Methodology

A programme theory (based on the literature, programme document synthesis, and a field visit) was developed using context-mechanism-outcome configurations to attempt to capture how an externally driven intervention promoted the formation of OPDs and led to particular outcomes. This was subsequently tested and refined by analysing the selected Cluster OPD case studies. Triangulation included a FGD with OPD members, SSIs with key informants (village leader and/ or community health worker and field manager), observation and key document review. Data was transcribed and translated into English and grouped into themes.

Context-mechanism-outcome configurations were refined between site visits and tested at subsequent sites.

What is a “realist evaluation approach?”

In contrast to conventional impact evaluation approaches where the core question is whether a programme works, the realist evaluation approach, developed by sociologists Pawson and Tilley in 1997, theorises that programmes “work for certain people in certain circumstances”(Hewitt et al., 2012) . Thus realist evaluation endeavours to explain “What works, for whom, in what respects, to what extent, in what contexts, and how?”(Westthorp, 2014). Rather than analysing the whole programme, this approach allows mechanisms to be analysed and can use quantitative and/or qualitative data to refine the theory underpinning a programme and explain the “for whom and how” components of a programme’s successes and failures (Hewitt et al., 2012).

Advantages of a realist evaluation approach in this context

The use of a realist evaluation methodology contributed to a better understanding of some of the contextual factors and mechanisms that may need to be considered in terms of the **formation and function** of OPDs. It provided a structure to consider process rather than impact and provided the means of assessing some of the contributing factors, such as the physical environment and group composition, that may enhance or detract from an OPD's ability to be formed and function. Knowledge about these types of factors is essential to understand how OPDs can form, as well as be effective.

The model used within this study involved the initial involvement of an NGO, an external entity. The realist evaluation methodology allowed the researchers to unpack how and why this model was thought to be useful. Providing depth around this aspect is essential to establish which factors were instrumental in OPD formation, in order to facilitate the development of OPDs elsewhere.

As in the preceding study, the methodology had similar advantages to those already discussed in terms of utilising qualitative techniques. The process of triangulation from focus group discussions, interviews, observation and document review enhanced the validity of the context-mechanism-outcome configurations.

Limitations of using the methodology in this context

This research methodology and the analysis required considerable researcher expertise, which may limit its use to places where such expertise is available.

From this study it was not possible to prioritise the importance of the mechanisms that were discussed. However, it provided a range of considerations that are at play in the establishment of OPDs by an external entity, and this can be considered in the formation of OPDs elsewhere.

The cross-sectional methodology made it difficult to differentiate the specific contextual factors involved at various stages of OPD formation.

Similar to the other qualitative study, the realist approach had difficulty including those with significant intellectual disability and communication disabilities, and it is difficult to determine if findings are generalisable to other parts of India or other countries.

This type of methodological approach tried to answer questions around

programme theory and process rather than effectiveness per se and needs to be used in conjunction with other approaches that evaluate overall impact.

Study 3. The impact of participation in Disabled People's Organisations on the social networks of persons with disability in Sunsari, Nepal and Uttarakhand, India (Montgomery J et al)

Study methodology: Mixed Methods, Social Network Analysis with Focus Group Discussions

Aspect studied: Impact

Detailed Methodology

Social Network Analysis (SNA) was used to compare the social connections of OPD members prior to and several years after joining the Cluster- initiated OPD. A representative sample of 8 members was selected from the Cluster Case Study according to age, gender and type of impairment. Inclusion criteria were: OPD member and self-identified as having disability. Exclusion criteria were: <18 years of age, recently joined member (less than 12 months) or irregular attendance (<50% of meetings attended in the previous year). Modified 'position generator' surveys were developed to gather data about OPD members' social connections. Contacts were defined as acquaintance, friend or family member, and it was identified whether the relationship and type were different prior to joining OPD. Collation and analysis were achieved using NodeXL, and network maps were developed according to a Harel-Koren Fast Multiscale algorithm.

Four FGDs were done with the 16 OPD members and key staff of the Cluster-facilitating NGO. Questions covered the social aspects of OPD involvement. Trained research assistants then transcribed and translated these into English. Thematic analysis identified key themes and sub-themes.

Advantages of SNA with FGDs when studying OPDs

By using the SNA methodology, assessments and comparisons were made regarding the quantity and extent of social connections of OPD members before and after joining an OPD. It allowed differentiation of where or with whom the maximal changes in their social network occurred. For example, connections were increased between OPD members; however little change was noted in their

connections with health and community services. This methodology is specific to the issues of social connectedness that were being researched.

Combining the quantitative methodology of SNA with the qualitative approach of FGDs increased understanding of how increased connections impacted individuals, both negatively and positively, and allowed the value of social connectedness to be delineated. The mixed methods process also provided triangulation and thereby enhanced the study's overall validity.

Limitations of the methodology in this context

This approach to SNA, done through single survey, relied on the recall of participants regarding changes in their relationships from when they joined the OPD, up to the period when the data was collected. This might have been difficult for participants and especially for those with cognitive disabilities. It also required participants to be able to verbalise and comprehend the extent of their relationships, which may have been difficult for people with more severe disability or intellectual disability.

Again, generalisability is an issue due to the small sample sizes used, although this is the only study (of the five included) which incorporated people from outside India (i.e., from Nepal).

Conducting and analysing SNA is complicated and requires specific expertise, potentially limiting its use as a methodology in other contexts to those where researchers have training and experience in this area.

SNA in itself specifically looks at social connectedness and does not evaluate other impacts that participation in OPDs might have.

Study 4. DPO membership has immediate transactional benefits as well as personal impact (Butcher et al., 2021)

Study methodology: Qualitative (Participatory Action Research) - Videovoice

Aspects studied: Function and Impact

Detailed Methodology

Purposive and convenience sampling was used to recruit 19 participants – 13 persons with disability who were OPD members and 6 carers of OPD members.

Inclusion criteria were: age > 18 years, able to follow instructions and communicate verbally, and having been OPD members for longer than 6 months.

Field staff were trained in research and video recording, interview and facilitation skills and supplied with a Videovoice manual.

The Videovoice methodology followed a modified version of Hergenrather's ten-point framework for Photovoice (Hergenrather et al., 2009) by utilising video in the place of photography. Participants were required to take 2 minutes of video footage that showed the impact that OPD membership had on their lives. Consequent interviews with field staff investigated participants' ideas and motivations within their clip. Interviews were recorded, transcribed and translated into English. Data included in the final analysis were transcripts from narrated videos, SSIs between field staff and participants, and additional FGDs. Analysis assigned the data under predefined categories which included skills, social, personal information/education and material. This was then coded, thematically analysed and validated with field staff.

Advantages of using this methodology-Videovoice with SSIs and FGDs

A qualitative study of this nature helps to determine how and when OPDs might have an impact, and particularly the mechanisms and stories that illustrate these factors.

Apart from providing research data regarding the impacts of OPDs on persons with disability, this participatory video methodology enabled active involvement and an avenue for self-expression. Participants had the chance to film whatever was important to them, minimising the constraints potentially present in more conventional research methodologies.

An added by-product of using this approach was that the process of producing the videos empowered OPDs to advocate for the roles and rights of persons with disability within their communities.

Limitations of using Videovoice in this context

The Videovoice methodology required significant technical and learning ability on the part of the participants, as well as the ability to construct a narrative. This may make it difficult to use where technical skills are lacking, or where people have more severe disability or intellectual disability. The use of a Smartphone video camera also requires the participant to have vision, hearing and the ability to hold and manipulate the device.

Again, the small sample sizes in qualitative research limits the generalisability of the findings.

Study 5. Disabled People’s Organisations increase access to services and improve well-being: evidence from a cluster randomized trial in North India (Grills et al., 2020)

Study methodology: Cluster Randomised Intervention Trial

Aspect studied: Impact

Detailed Methodology

A cluster randomised trial evaluated the impact of cluster initiated OPDs. A baseline survey was done initially in 2014, using the RAD survey tool to assess well-being, community participation and access to services. People with disability were identified in each village. This was followed by Cluster NGOs facilitating the formation of OPDs. The subsequent end-line survey was done in 2017 using the RAD tool. Thirty-nine villages were purposively selected from five areas in Uttarakhand. While 20 villages were allocated to the intervention arm where OPDs were facilitated (272 people), 19 villages were allocated to the control arm where no OPDs were facilitated but normal disability work continued (211 people).

OPDs were encouraged and supported to have weekly meetings, monthly training sessions on OPD formation, monthly visits by the research team for support, and biannual public events. Persons with disability were encouraged to visit the block and district offices and make three visits to the disability commissioner. OPD members also visited other OPDs, and livelihood initiatives were started.

Advantages to using this methodology

This is the first level II quantitative study that has been done to evaluate the impact of OPDs on persons with disability.

The advantage of a quantitative methodology in general is that not only can the degree of impact be measured, but its significance can also be calculated. In this way the impacts can be measured, quantified, and consequently evaluated against each other, and the significance of individual impacts can be determined. However, a tool to measure this was required. The development of the Rapid

Assessment of Disability (RAD) tool preceded this study (Marella et al., 2014). This validated tool measures elements across seven domains of access and participation, enabling standardisation before and after measurements of impact.

The control group provided a means to compare the measured impacts for persons with disability who were participating in OPDs, with those who were not. This gave an opportunity to measure the impact of OPDs on persons with disability and also to gauge whether OPDs provided an added advantage beyond what was previously available.

The cluster randomised approach is ideal in elucidating effects across communities where the intervention is by group.

Limitations to using a Cluster Randomised Intervention in this context

Recruitment bias has been raised as an issue in cluster randomised control trials (Chan et al., n.d.). There were attempts to include all persons with disability from the selected villages in the study by using a key informant approach. However, as with the other studies in this case study, it was difficult to assess whether this approach identified all people with disability.

The generalisability of this study may again be limited, given that the intervention was only undertaken in two districts within a single area in India.

The measurement of impacts that were made was limited to those that could be identified using the RAD tool. This may not have identified all of the possible impacts. It also could not provide the depth that the qualitative, more open-ended approach provided.

DISCUSSION

This Case Study has examined five research approaches used in Uttarakhand State of North India, which together evaluate the formation and function of Organisations of Persons with Disabilities. It has explored some of the advantages and limitations of using different methodologies to study the phenomena of OPDs. These five studies represent some of the most comprehensive bodies of research on a specific group of OPDs. This is significant given that Organisations of Persons with Disabilities are promoted as important in improving the participation and well-being of persons with disability (Callus & Camilleri Zahra, 2017), yet there is sparse evidence about OPD formation, function and impact in low- and middle-income countries (Young et al., 2016).

Of note, the randomised controlled trial provided the first RCT level evidence of the positive impact of OPDs, which was further supported by the qualitative studies. Within this Case Study, OPDs were generally found to have a positive effect on participation and well-being across a variety of domains (Butcher et al., 2021; Grills et al., 2020; Montgomery et al.; Leung et al., 2019). OPDs were also found to improve the social connectedness of participants (Butcher et al., 2021; Grills et al., 2020; Montgomery et al.; Leung et al., 2019), participants' self-confidence (Butcher et al., 2021; Leung et al., 2019; Young R et al., 2016), the ability for self-advocacy and persons with disability having their opinions heard (Grills et al., 2020; Leung et al., 2019), participation (Grills et al., 2020; Leung et al., 2019) and access to government services and assistive devices (Butcher et al., 2021; Leung et al., 2019; Young et al., 2016). In the formation of OPDs a number of factors were found to be important including initial NGO support, networks with other OPDs, and village leader support (Young R et al., 2016).

The inclusion of different qualitative and quantitative methodologies within this Case Study is informative. The debate around using qualitative versus quantitative methodologies is not new, with both paradigms having distinct advantages and limitations. This Case Study suggests that a mixed methods approach can be useful to study complex phenomena like a social movement- a sentiment supported by the literature (Beail, 2014; Hartley & Muhit, 2003; McVilly et al., 2008; O'Day & Killeen, 2002). Ultimately this Case Study demonstrates that the use of a variety of both qualitative and quantitative methodologies provides a rich and comprehensive understanding of how OPDs impact on persons with disabilities and their families, far more than any of the studies can provide individually. It is the quantitative study that sheds light on the statistically significant effect that OPDs have on well-being and access, but the qualitative studies give information as to how and why this occurs.

The quantitative study included in this Case Study represents the first randomised controlled cluster trial on OPDs in low- and middle-income settings. Previous to this, the one quantitative study identified in Young's literature review was a survey (Kumaran, 2011), and one mixed methods study with a questionnaire and Focus Group Discussions (Stewart & Bhagwanjee, 1999). A RCT provides quantitative data that measures the amount and type of impact that OPDs have on members. The objectivity inherent in quantitative methodology gives greater reliability and validity to the findings; however, they are more costly to run, with greater sample sizes required. They can provide measurement of impact and

incorporate statistical analysis but are not able to provide the in-depth analysis that the qualitative approach can.

Similar to the existing literature reported in the literature review by Young et al (Young et al., 2016), the majority of the studies that were included within this Case Study were qualitative. Within this Case Study, the qualitative approach of researching OPDs has a number of advantages. It provides a medium to examine what OPDs mean to members, their perceptions about how participation has made an impact on their lives, and their personal narratives and stories. The smaller numbers involved makes it an easier research method in terms of recruitment of participants and costs of completing the research. The ability to extract the salient themes that emerge means that there is more scope to design appropriate quantitative studies that do not miss important domains. In contrast, they can also function alongside existing quantitative studies to delve deeper into the aspects that a quantitative methodology is unable to provide answers to (O'Day & Killeen, 2002).

By using a variety of methods with their own inherent advantages and limitations, different information was gleaned about OPDs; this would not have been possible by using any of the methodologies in isolation. For example, the realist evaluation provided an understanding of the contexts within which and through which mechanisms an OPD works. The participatory approach of using Videovoice had the advantage of gaining participants' personal perspectives about the impact OPDs had on their lives and the network analysis used visual mapping to illustrate how peoples' networks grow through participation in an OPD.

The difficulties of representing the voices and issues of the broad spectrum of people with disability within a research context have been documented (McVilly et al., 2008). Each of the 5 research approaches included in this Case Study faced similar issues in that they excluded people with certain disabilities. Each different methodology will be more or less accessible to some over others, depending upon the nature of the disability and the features of the methodology. The inclusion of those with hearing and speech impairments, severe disabilities and intellectual disabilities remains an ongoing challenge, with more work needed to explore how to ensure these groups are represented in the published literature so that their needs are not forgotten. The quantitative survey was perhaps less problematic than the qualitative approaches that often required processing of more complex questions and the use of tools like video. Approaches from the

literature that have been used to address this problem have included involving the persons with disability in some capacity within the research team in the roles of advisors, collaborators or leaders and controllers of the research (Bigby et al., 2014), asking simple open-ended questions and ensuring questions are non-leading (Beail, 2014), using observational methodologies and collaborative approaches over longer periods of time (McVilly et al., 2008), and utilising appropriate communication aids.

Another approach to help include people with different disabilities is to incorporate the voice of their carers but, under the rights-based approach advocated by the UNCRPD, people with disability should be facilitated to speak for themselves (Callus & Camilleri Zahra, 2017). There are limitations that are determined by the extent of the disability that some people have, that make it difficult for them to have their voices heard within a research context. In these situations, this Case Study shows that incorporating the voices of carers can be informative. In effect, these carers can often play the role of interpreter or communication aid for the person with disability. None of the included studies differentiated whether the themes that were identified were more salient for those with disability or for their carers without disability. It is possible that they may not have the same views on what is actually meant by impact in the OPD context.

Interestingly, in many of the included studies, individuals under 18 years of age were specifically excluded from involvement in the research. It is not clear in the literature as to how often those under 18 participate within Organisations of Persons with Disabilities, and no groups that specifically cater to youth were identified. This is despite there being very limited research regarding youth with disabilities in developing countries (Groce, 2004). Whether there is benefit from including young people and how they should be included within OPDs would be an area of future research.

A common finding across all 5 studies was the importance of external entities (usually an NGO) in supporting the formation and function of OPDs. Importantly, the NGOs were not a member of the OPD, satisfying the accepted definition of an OPD as an organisation that is composed of, governed and led by persons with disabilities (Deepak et al., 2013; United Nations General Assembly, 2016). The realist evaluation indicated that this initial NGO support was one of the aspects that led to some of the positive impacts described. It described how this initial support was important in terms of recruiting OPD members, initial funding, and modelling of organisational and governance strategies. In the few studies in the

literature that did describe it, the OPD was either initiated by persons with disability themselves (Armstrong, 1993; Stewart & Bhagwanjee, 1999) or the development of the OPD was facilitated initially by an external entity (Polu et al., 2015).

None of the included studies were undertaken after NGO support had been withdrawn, and therefore no information was collated around the factors that might lead to the effective continuation of the OPD after NGO support is withdrawn, nor how NGOs might approach withdrawal of support to ensure that the OPD remains viable. Furthermore, it is difficult to comment on the durability of results about OPDs, given that the timeframe for these studies was over 3 years only. These would be areas that would benefit from future follow-up research.

Another factor inherent in many of the included studies, including the cluster randomised control trial, was the involvement of OPD members with other groups for the purposes of forming networks. Network approaches between OPDs have also been described in other literature (Armstrong, 1993; Coble, 2013; Deepak et al., 2013; Hemingway & Priestley, 2006; Kleintjes et al., 2013; Miles et al., 2012). The value of the Uttarakhand Cluster as a network has been reviewed in previous studies (Grills et al., 2012; Grills et al., 2016). The realist evaluation described this process of visiting other OPDs as being useful in terms of modelling group function, increasing enthusiasm, sharing knowledge, and increasing confidence, which in turn led to earlier group formation, more rapid transfer of responsibility from the NGO to the OPD members, and increased participation in society. Future studies would need to assess whether this network and linkages component is essential to the successful formation of OPDs in other contexts.

One theme that could be further explored is determining whether OPDs improved financial well-being and livelihoods. The outcome was not clear and differed between the studies. Within the RCT (Grills et al., 2020), employment was the one access indicator that did not show improvement; however the study by Butcher et al (2021) suggested access to methods of livelihood - such as raising chickens - did occur, and Leung et al (2019) found variables impact on income generation. It is possible that whilst OPDs might not have resulted in increased formal employment, they may have resulted in an increase in informal roles and self-employed activities such as subsistence farming. Either way, some form of economic analysis would help to better understand the OPD phenomena impact on livelihood and economic security.

Limitations

This Case Study is based on only 5 research studies, all done in a similar context. Further research in other contexts, using additional methodological approaches would provide additional insights.

Most of the included studies either collected data at a single period in time and/or collected data in the early stages after OPDs were formed. It is not clear whether impacts identified early on, after groups formed, would be either sustained in the longer term or whether the nature of the impacts may vary and change over time. Longer term follow-up would be necessary to explore this, potentially in the form of longitudinal studies.

A limitation of a Case Study approach is that the geographic area is limited – in this case to Uttarakhand in Northern India. It is unclear whether the same impacts and factors would be apparent for other OPDs in other geographical, economic, and cultural contexts. However, the in-depth contextual data gathered from using this multi-pronged approach helps to understand what might or might not work in other contexts.

CONCLUSION

This Case Study demonstrates that OPDs can be effective, and the different studies outline how and why this was so. It demonstrates the value of multiple and mixed methods approaches to study a complex phenomena such as the formation and functioning of OPDs.

It highlights the importance of using a variety of methodologies, in order to understand different aspects of OPDs. Each methodology has its own inherent strengths and weaknesses; however by utilising a spectrum of approaches it is possible to begin to construct a more comprehensive picture of Organisations of Persons with Disabilities and their application for people with disabilities.

ACKNOWLEDGEMENT

The authors would like to thank CHGN Uttarakhand Cluster for hosting the research, CBM India for supporting the OPD intervention and research, and Bethany Carr of the Nossal Institute of Global Health, Australia.

No potential conflict of interest was reported by the authors.

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