EXPERIENTIAL ARTICLES

Exclusion through Attempted Inclusion: Research Experiences with Disabled Persons' Organisations (DPOs) in Western Zambia

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ABSTRACT

Partnership with disabled persons' organisations (DPOs) is often presented as one mechanism to ensure the inclusion of persons with disabilities in research that concerns them. In working with two DPOs in Western Zambia, we learned that one of these groups was organised in a way that differed from our own presumptions and the descriptions of DPOs in literature: the group was fluid in membership and willing to re-formulate itself according to the priorities of visitors. From this we understand that limiting research partnerships to DPOs, as typically described, could lead to the inadvertent exclusion of people involved in many different forms of organising by persons with disabilities.

Key words: *Disability self-advocacy, qualitative research, participatory research, Zambia*

INTRODUCTION

It is well established that persons with disabilities should be included in the direction of research about disability (Oliver and Barnes, 2010). Disabled Persons' Organisations (DPOs) have been seen as a mechanism to provide persons with disabilities a collective voice for the purposes of democratic self-representation to external bodies (Enns, n.d.). For these advantages, researchers have approached DPOs as partners in inclusive research collaborations (e.g., Suarez-Balcazar et al, 2005; Lorenzo and Joubert, 2011).

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Recognising that the context in which a DPO is formed will influence its nature (Young et al, 2016), we were open to the possibility that DPOs could take any one of many forms. Despite this, we discovered that we were unprepared for some forms of collective organising by persons with disabilities. Owing to certain presumptions, and by discounting the forms of organising by persons with disabilities with which we were unfamiliar, unforeseen exclusion criteria were created. Therefore, the purpose of this experiential account is to encourage more inclusive disability research practices through the examination of a case of mistaken presumptions about the nature of a DPO.

A constructionist qualitative research study was initiated, to learn about the lived experience of disability in Western Zambia, recruiting DPOs as participants (Cleaver, 2016). The intention was to create more opportunities for the participating DPOs to direct the research as the study progressed.

Research Context

Western province has the highest levels of poverty (Central Statistical Office - CSO, 2012) and the highest prevalence of disability in Zambia (Eide and Loeb, 2006; CSO, 2012). Although the population of Western province is 85% rural (CSO, 2012), most of the administrative and business activities are concentrated in the largest town of Mongu.

Organising persons with disabilities in Zambia is officially recognised in the Persons with Disabilities Act (Zambia, 2012), which defines “organisations of” and “organisations for” persons with disabilities. Zambia’s most prominent DPOs focus on specific disability categories, have countrywide jurisdiction, and are part of the Zambian Federation of Disability Organisations (ZAFOD). All of these prominent DPOs are recognised by the Zambian Agency for Persons with Disabilities (ZAPD). At the time of the study, a small number of persons with disabilities in Western Province had created local chapters of the prominent national DPOs, but a larger number had become involved through neighbourhood DPOs. The provincial office of the governmental Zambian Agency for Persons with Disabilities was aware of approximately 30 neighbourhood DPOs in Western Province, nearly all of which were based in Mongu.

The plan was to recruit one DPO in Mongu and one DPO in a rural area, as this study aimed to learn about the realities of life in both urban and rural settings. There was a suspicion that some DPOs, especially in rural areas, might operate in unconventional ways and be unrecognised by the government. To guide the recruitment for the study, a list of presumptions were set down that would be applied holistically to determine if a group should be considered a DPO. The presumption was that a DPO would be a collective that assembled because of a common interest in disability. It was also presumed that a collective would have a consistent pre-established identity through membership, a name, and some sort of operating principles or norms.

Engaging a Rural Disability Collective

The recruitment of DPOs began by contacting government offices that had frequent interactions with persons with disabilities.

The recruitment of an urban DPO in Mongu was straightforward. A government officer suggested that we contact the chair of one of the neighbourhood DPOs to request a members' meeting. After a presentation was made, this urban DPO used its established, consensus-based decision-making process and agreed to participate in the research. The research process was carried forward by approaching individual members for their consent to participate, and by arranging individual interviews and focus group discussions.

To recruit a rural DPO, the process used in Mongu was replicated, while remaining cognisant that there was no registry of DPOs outside of the major towns. Two district-level offices of a government agency assisted with the initial task of identifying DPOs. In one of these districts, we were introduced to a school teacher with a disability. When the purpose of the study was explained, she offered to initiate a group. However, the offer was declined since the target was pre-established groups, not groups formed exclusively for the study.

The second district was one in which there had formerly been a leprosarium. Some of the people who were treated for leprosy decided to remain at the site even after the leprosarium was closed due to a decreasing number of new cases and health sector reform (Kapata et al, 2012). It was generally known in the district that there were persons with disabilities in the village where the leprosarium used to be. The government officers had a history of engaging collectively with persons with disabilities in this village, including persons with and without a history of leprosy. The descriptions of past engagement, particularly a recent distribution of food and clothing, seemed to be like interactions with a DPO – there was ongoing dialogue with leaders, records of meetings, and lists of DPO members identified for various initiatives – even though the DPO's specific organisational structure remained unclear.

The timing of the study's recruitment coincided with the need for the government office to provide the DPO with a programme update; therefore a meeting was called for the two purposes. A presentation about the research was made at this meeting. It came as a surprise that many who were present immediately agreed to participate. The presumption was that the DPO would first need time to discuss the matter internally. None of the meeting attendees were against participation in the research, so it was proposed that the researchers and the DPO leaders would collaborate to plan the individual consent process and data collection activities. The researchers were presented a list of 9 individuals with disabilities who were identified as leaders.

To seek the consent of individual DPO members, the members had first to be identified. The district-level government office presented two lists of names - one with 12 people and another with 60 (which also included most of the 12 from the first list). Since the government office's ongoing services were oriented to households and not organisations, the staff were not troubled by the discrepancy in membership numbers. Meanwhile, the researchers presumed that the explanation for the variability would become clear in time, but that the larger number was likely to be the maximum group size. Again, it came as a surprise when the leaders submitted the list of DPO members: there were more than 100 individuals named.

The study was designed with the intention of speaking personally to each of the DPO members. With over 100 members on the list, this would no longer be possible. The DPO leaders were informed that the study design would be reviewed, with the possibility of revising the eligibility criteria to only include smaller DPOs. In response, the leaders offered to immediately reduce the size of the DPO to ensure that the research continued as per the original schedule. This caused some confusion: the possibility that the DPO would re-configure itself according to the study logistics seemed to violate the logic of DPOs. Are DPOs not created by persons with disabilities, on their own terms?

Meanwhile, the group leaders expressed their frustration. From their perspective, it appeared that the researchers were not being straightforward about what was wanted. Did the study intend to include children and the elderly, or only adults with disabilities? Which disabilities? People from which villages? According to the leaders, they had received many visitors, but had never seen visitors with plans that they considered to be so vague and poorly-developed. Despite these frustrations, the leaders were very clear that they wanted the study in this community to continue.

Uncovering the Explanation of the Disconnect

The research continued without changing the schedule but by modifying the original plan. Abandoning the notion that the rural DPO had a defined membership, the attendance in the first round of focus group discussions was limited to the number of people who could fit in the room for each session. Although this strategy differed from the original plan of comprehensively including all members, the focus group discussions ran relatively smoothly. Fifty-nine people participated in one of four sessions. From these participants, 19 persons with disabilities were purposively selected for individual interviews.

Through the data collection activities, more information about this community was gathered from the research participants. They spoke about the many individuals and organisations that had come to the community to initiate projects. They had found some of these projects very beneficial; in other cases, the visitors made promises but never returned to fulfil them. However, one element that the previous visitors had in common was that all the projects were initiated with detailed, pre-established plans. The community was welcome to join in these plans, but had minimal overt control over their initial design.

In the light of the participants' accounts of projects initiated by previous visitors, their approach towards the current study seemed very logical. It was as if the leaders expected the current researchers to define more specific terms, after which they – and individual community members – could respond. Seen from this perspective, it would be in the interest of the disability collective to avoid developing a formal structure, and instead maintain the flexibility to re-develop according to the initiatives declared by visitors. In this context, the presumption that a pre-established structure would be a definitive sign of organising by persons with disabilities would be erroneous. Flexible and responsive organising would be better positioned to contribute to projects that matter to persons with disabilities.

Reflections

Despite attempts to remain open to multiple forms of organising by persons with disabilities, we found ourselves unprepared for the flexible structure of the rural DPO. This has caused us to question our presumptions about DPOs, and the possible origin of these presumptions.

Typically DPOs seem to fall into 2 broad categories, based upon the profile of the membership: in "organisations of", persons with disabilities are the majority of the members, whereas "organisations for" have a membership that is predominantly, or even entirely, without disability (Zambia, 2012). Inherent in this categorisation is the notion that the members will be identifiable and quantifiable. According to the typology of organisations of/for, the rural DPO in this study is essentially unclassifiable: calculating the percentage of members with disabilities is impossible when there is no formal membership from which a percentage can be calculated. Inadvertently, the typology of organisations of/for makes formal membership a precursor for a disability collective to be considered an organisation. It is suggested that this typology also influenced the presumptions that were made in designing the recruitment for this study. These presumptions led to a narrow consideration of DPOs, and therefore of eligible collectives of persons with disabilities.

The eligibility criteria that were developed for this study had implications that were not appreciated at the time when the study was designed. In hindsight, the situation of organising in the first rural community (which the research deemed ineligible) might not have been very different from that of the second rural community (which was deemed eligible). The second community, which was eventually selected to be the “rural DPO,” was considered to be eligible because they looked like they were a formal entity, even though it was later discovered that they were not. In the first community, no signs of pre-established (formal) organising by persons with disabilities were apparent and therefore the researchers were unable to learn about any organising that might have been happening on an informal basis.

The experience of this study has brought awareness that a researcher’s consideration of what constitutes a DPO could affect the types of organising by persons with disabilities that are included in research and those that are excluded. To move beyond this form of exclusion, it is proposed here that there should be more conscious consideration of organising by persons with disabilities and DPOs. We contend that organising by persons with disabilities and DPOs are one and the same, and worth considering in many different formulations. Nonetheless, we are open to reasoned disagreements as we collectively try to balance a celebration of diversity with a recognition that definitions and categorisations can be useful in some instances.

CONCLUSION

Collaboration with DPOs is one potential strategy for more inclusive disability research, but only if there is conscious consideration of the types of organising that are included and excluded by this approach. In this research on disability in Western Zambia, we sought to identify and collaborate with DPOs, but found that our capacity to do so in the rural context was limited by presumptions that were informed by a pervasive system of categorising DPOs. Our experience of coming to understand a rural DPO and the context in which it was developed, has alerted us to the possibility that DPOs can be formulated in ways that are more flexible than those that we could foresee. Expanding the consideration of what can be considered a DPO opens the possibility of including disability collectives that would otherwise be overlooked in research on disability.

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