
RESEARCH

Participatory Research in Disability in Low- and Middle-Income Countries: What have we Learnt and what Should we Do?

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Disability scholarship has embraced participatory research methods to support the collection of more relevant, ethical and potentially higher quality data. However, most of the relevant literature focusses on high-income settings. Discussions on the challenges and opportunities in using these approaches in low- and middle-income countries (LMICs) is sparse. The aim of this paper is to critically reflect on the participatory approaches used in disability research in LMIC contexts by the International Centre for Evidence in Disability to learn lessons for future research. Studies were selected from ICED's portfolio to consider participation at different stages in the research cycle and to critique the extent to which this was achieved. Studies set in the Gaza Strip and Malawi demonstrated the potential for involving people with disabilities in research planning through collaborative workshops and steering groups. Studies highlighted the opportunities and practical strategies for including disabled researchers in quantitative (India) and qualitative (Nepal) research. In Colombia, the use of participatory video enriched the interview data collected concurrently. Experiences in Malawi highlighted challenges of participatory analysis and how these could be addressed. In Vanuatu, PhotoVoice was used in dissemination, which helped in conveying lived experiences behind data. Similarly, in Brazil, involving caregivers of disabled children in dissemination workshops and publications provided important insight and potential for impact. Inclusion in analysis steps is potentially more challenging. In conclusion, meaningful participation of people with disabilities throughout the research cycle is achievable in LMICs and can potentially improve research quality and lead to more relevant programmes.

Keywords: Participatory research; disability; inclusion; qualitative; quantitative; low- and middle-income countries

Introduction

The Disability Rights Movement holds strongly to the principle of 'Nothing about us, without us', emphasising that people with disabilities must have voice and control of activities related to them (Charlton 1998). The development of policies and programmes on disability must therefore be guided by the preferences and needs of people with disabilities themselves to ensure that they are relevant and appropriate. Evidence on disability is generated through the conduct of research, which must also ensure the 'full and effective participation and inclusion' of people with disabilities (UN 2006). Historically this has often not been the case: research has been done 'on' disability and 'on' people with disabilities, without considering what they may have to say. This exclusion may be even more pronounced in low- and middle-income countries (LMICs) as resources for research are generally lower.

The importance of participatory methods to achieve ethical and equitable research practices, and potentially higher quality data, are well established (Institute of Development Studies 2013). Essentially, these are approaches that transfer power from the researcher to the research subjects, to varying degrees, so that people with disabilities are active partners in the research process. Participation throughout the research cycle can influence the definition of the research question, identification of acceptable funding sources, selection of methods that enhance recruitment and pertinent data collection, and bring nuance into analysis, interpretation of findings, writing up and authorship.

There are different ways of conceptualising participation (Danieli & Woodhams 2005). The ladder of participation was originally developed to consider citizen participation (Arnstein 1969). It can be relevant when considering participatory research, including disability-inclusive research, whilst acknowledging that it was intended as a rhetorical device

rather than a fixed hierarchy of participation (Holland et al. 2008). At the lowest level, there is non-participation, or even manipulation, for instance, forcing people to take part in a study in order to benefit from a service. Nominal participation, or tokenism, is one rung higher up the ladder and includes informing or consulting with people with disabilities, such as inviting them to attend meetings about research that has already been designed. The next level up is partnership, or active participation, where people with disabilities may be engaged in designing research, collecting data and voicing opinions. This level and up may also be described as co-produced research, where there is mutual support and cooperation between researchers with and without disabilities towards a common goal (Hickey 2018). The highest level is effective participation, through delegated power or citizen's control. Here, people with disabilities make most decisions about the research, including budgetary decisions, or even have full ownership of the process (emancipatory research) (Barnes 2003).

Some good practice examples exist with respect to participatory disability research, particularly from high income settings. One interesting example is the Lived Experience Advisory Panel (LEAP) project in the UK, which included people with lived experience of using mental health services in the research in order to inform programme improvements (Pinfold et al. 2015). The authors concluded that their research was higher quality and more programme/policy relevant as a result of the integration of lived experience and local expertise, reduced the power hierarchy between researchers and other stakeholders, and established more transparent processes for reaching consensus (Pinfold et al. 2015). Another example is the Dementia Enquirers project, where British people with dementia have been involved in designing and carrying out small-scale research on dementia (Berry et al. 2020; Davies et al. 2021). These projects have been designed in accessible ways throughout the research cycle and so end up being about what matters to people with dementia.

Certain research techniques can also support participation in research. For instance, PhotoVoice is a visual method where research subjects take photographs to document experiences they have and challenges they face (PhotoVoice 2019). It has been used in different settings to allow people with disabilities to express the issues they face and the key impacts of their disability in their lives (Dassah, Aldersey & Norman 2017; PhotoVoice 2019). Other innovative methods and approaches, such as the use of photography and film, may also support the conduct of participatory research (Aldridge 2007; Wickenden & Elphik 2016; Wickenden & Kembhavi 2014). Funding mechanisms, such as Disability Research on Independent Living & Learning (DRILL 2020), have been established to support research projects about disability led by community organisations working for and with people with disabilities.

In reality, participation in disability-related research is not undertaken extensively. This gap is noted particularly in LMICs, where the challenges of lack of funding, availability of trained disabled researchers and accessibility are potentially magnified, notwithstanding certain exceptions (Albert & Harrison 2005; Berghs 2017; Greenwood 2016, 2017; Wickenden & Elphik 2016; Whitzman, James & Poweseu 2013; Wickenden & Kembhavi 2014). For instance, a recent review of using PhotoVoice to capture the experience of people with physical disabilities identified 20 papers, only 3 of which included data from LMICs (Dassah, Aldersey & Norman 2017). Anecdotally, where participation does occur in LMICs, this is usually in terms of consultation on methods and findings and is therefore relatively tokenistic. The reasons for these failures may include practical considerations, such as accommodations that must be planned and financed to promote inclusion, or the often relatively small pool of disabled researchers available, particularly in LMICs. However, the overriding cause is likely to be the lack of awareness of the importance of participatory methods, knowledge of effective approaches or enticements for their use. As a consequence, disability research is failing to capitalise on the wealth of experience and knowledge of people with disabilities, and this may, in turn, create poorly informed policies and programmes (Lang et al. 2019).

The International Centre for Evidence in Disability (ICED) is a research group within the London School of Hygiene & Tropical Medicine (LSHTM). Its focus is on the conduct of research about disability in LMICs in order to inform policies and programmes. Different participatory approaches have been used in our work over the last decade. The aim of this paper is to critically reflect on the participatory approaches used in disability research in LMIC contexts by ICED to learn lessons for future research.

Case Studies of Participatory Research

We selected a range of case studies of participation from ICED's portfolio of work to allow us to reflect on the benefits, challenges and lessons learnt on achieving participatory research in the context of disability in LMICs. These case studies were selected to represent different aspects of the research cycle, geographic areas and approaches to encouraging participation. They are presented by research cycle stage, which cuts across different examples. Researchers involved in each project (including one disabled researcher) reflected on the merits and difficulties with the approach taken, and then the wider group added further comments.

Planning research: Gaza Strip and Malawi

The first step in research is defining the question to be investigated. This step is complex and usually requires input from researchers as the question needs to be appropriately targeted (i.e., neither too niche nor too broad) and not have been answered already. The topic must also have practical policy and programme relevance, which requires input from stakeholders. Ideally, people with disabilities identify the question themselves so that topics investigated are important to them. For example, the DFID/ESRC-funded Levers of Success study was devised by a British disabled researcher in

association with African organizations of persons with disabilities (OPDs) and NGOs. Success was defined by people with disabilities themselves, and people who had experienced success in their lives shared their stories (Shakespeare et al. 2019). A second option is to include people with disabilities in the definition of the research question. As an example, ICED are working with CBM and Atfaluna Society for Deaf Children to develop guidelines on mental health and psychosocial support (MHPSS) for children with hearing loss in the Gaza Strip. The need for these guidelines for LMICs was first proposed during a collaborative workshop with members of the D/deaf community and organisations focused on services for people with hearing loss in LMICs (including DeafKidz International and CBM), as well as ICED researchers.

Another example of participatory approaches in planning studies from our work is from a qualitative study undertaken in 2019–20 in Malawi to explore reasons for the exclusion of children with disabilities from school. A preparatory workshop was held to finalise the interview guides and to train the fieldworkers. This workshop was attended by both researchers without disabilities and people with disabilities, who were linked to the national OPD and paid a per diem for their attendance. This latter group included people with a range of impairment types, including visual, hearing and physical. We therefore ensured that the space was accessible and that sign language interpretation and guides were provided. This workshop fostered collaboration, helping researchers become more sensitised to and knowledgeable about disability through their interaction with OPD members. This learning was further enhanced by the fact that the lead educator was himself disabled. Additionally, the disabled participants reviewed the interview guides, providing critical input as to how these could be improved and whether the protocols for identifying individuals for interviews were acceptable. Ideally, we would have directly trained people with disabilities to conduct the interviews; however, the OPD members included in the workshop did not speak the local languages. Furthermore, we were not able to identify people with disabilities with the required background training given the large gaps in research capacity in Malawi and other LMICs. Still, this is indicative of the cycle of exclusion where barriers to education leads to fewer people with disabilities with research skills.

Conduct of research

Quantitative data collection in India

ICED has undertaken a number of surveys, case control studies and impact evaluations, collecting quantitative data. Efforts have been made in different studies to include disabled data collectors, such as within an all-age population-based survey of disability in 2013–14 in Telangana State, India (Mactaggart et al. 2016). Here, data collectors were identified by an NGO livelihoods scheme supporting young women with mobility limitations. The women were responsible for conducting in-depth questionnaires with people with disabilities and their peers without disabilities about different aspects of their lives. The quality of data collection of the disabled researchers was at least as good as the other data collectors. Moreover, we perceived that the visibility of disabled women in the study teams supported de-stigmatising of disability in the predominantly rural communities where we worked. People with other impairment types were not included because the NGO partner only worked with women with mobility limitations.

There were also challenges to the inclusion of disabled researchers. During fieldwork, there were often limited accessible facilities available for water and sanitation, which is frequently the case in LMICs and which created difficulties for the disabled researchers. The fieldwork required travel across long distances to and from the communities, which was also challenging for the disabled researchers. Another concern was negative attitudes of several other study team members about the disabled researchers, which spurred inappropriate behaviour. For example, other team members, on occasion, delegated more menial tasks to the disabled female researchers or failed to include them in team decision-making. In future, addressing negative attitudes and cultural stereotypes amongst study teams during the training may help to ensure that inclusion of people with disabilities in study field teams is fully supported by all team members.

Qualitative data collection in Nepal

Inclusion of disabled researchers is arguably even more important during qualitative data collection, as the quality of information is more directly influenced by the rapport between the interviewer and interviewee. A range of strategies have been used by ICED, from training disabled researchers to supporting research led by people with disabilities.

Two research projects were implemented in Nepal in 2017–18 involving young people with disabilities as research associates. The first, 'Strengthening voices of adolescents', aimed to understand what was important for the wellbeing of disabled adolescents in Nepal (Bhatta et al. 2018). The second, 'Disabling Menstrual Barriers', explored the barriers to menstrual hygiene management (MHM) experienced by disabled adolescents and their caregivers (Wilbur et al. 2019). Young people with disabilities were central to the research process, from planning to analysis and dissemination. They were recruited through a competitive and open process and included people with physical, visual and hearing impairments. ICED researchers delivered a week-long training on how to conduct qualitative research. The workshop employed participatory approaches to promote greater ownership and active engagement of the young people. An inclusion focal point person was appointed to monitor the accessibility of the training activities and to act as a go-to person during the workshop so that the training could be flexible to needs throughout. Furthermore, the researchers were mentored by experienced researchers. The research roles varied over the lifetime of the project and as the researchers gained self-confidence and included leading/co-leading focus group discussions, in-depth and key informant interviews, analysing and interpreting data, planning advocacy and disseminating findings.

Challenges were varied and included inaccessible terrain and buildings, as some homes were not easily accessible for researchers who were wheelchair users. The emotional demands of the research was a key issue for every researcher, as interviews sometimes provoked thoughts about their own experience of growing up with a disability. This was an important safeguarding issue that had to be carefully managed. But there were also important positive aspects. The researchers with disabilities described how, overall, they found it an empowering experience. They contributed their lived experiences to the development of the topic guides and believed that they often achieved a good level of rapport with their interviewees, especially those with a similar disability. The research supported the co-production of an MHM intervention for women with intellectual disabilities, and it has been shown to be feasible and acceptable (Wilbur et al. 2019).

Participatory approaches to data collection in Colombia

Evidence generation can also be explicitly participatory. In Cali, Colombia, we used participatory video (Lunch & Lunch 2006) as a research method to help understand the impact of a community-based parent-support programme (Juntos) for caregivers of children with congenital zika syndrome (CZS) (Duttine et al. 2019). The Juntos programme itself was developed through participatory methods, as researchers worked together with families to identify their needs and to create the programme. Moreover, the programme was implemented through participatory approaches, as parents were encouraged to share their experience to facilitate peer-learning, and one of the facilitators was a mother of a child with CZS (Smythe et al. 2020). The participatory nature of the development and delivery of the programme were key reasons for its acceptability and potential impact (Smythe et al. 2020).

Nine caregivers of children with CZS took part in the participatory video process, which were used to identify the impacts that were most important to them. First, the group chose the primary question 'What was the most significant change that you noticed in the health and wellbeing of your child, and your family, since the beginning of the Juntos project?' Next, the participants shared their stories of caring for a child with CZS and together chose which participant's story would be filmed and why. Generally, this participatory process leads to one to three individual stories being chosen. In Cali, the participants preferred combining aspects of different caregivers' stories to make one video that represented a bit of them all. The group then learnt how to use a video camera, developed the video plan through storyboarding and finally filmed the video so that they had control over the whole process. Care had to be taken to ensure that particular caregivers did not dominate the process, as well as finding roles for caregivers who preferred not talking on camera (e.g., filmed feeding their child or could help with the filming). The final video can be found here: <https://vimeo.com/404644689>.

This process helped caregivers to deepen their discussion around themes by exploring key concerns as a community and deciding collectively how to best represent them creatively. Three of the most important themes included their feeling of empowerment, the new friendship they built with specific caregivers and the impact of what they learnt through the programme on their communication with their child. Notably, this approach allowed participation of caregivers of disabled children but not disabled children themselves as they were very young. Follow-on work is planned in Brazil that will focus on using participatory video with adults with disabilities themselves to understand their experience of accessing healthcare services.

Interpretation of data: Nepal, Malawi and Vanuatu

Participatory analysis of data is, arguably, particularly challenging as analysis requires specific skills and training, which may be lacking in LMICs given the dearth of both disabled and qualitatively trained researchers. Other options are available, however, in the absence of suitably qualified disabled researchers.

In the adolescent wellbeing research project in Nepal, the disabled research associates trained for data collection also contributed to interpreting the data. At the end of each day, the research team would meet and discuss the findings and emerging themes, reflecting also on the wider context and their potential biases. Through this process the team identified issues that they wanted to explore further in future interviews. The disabled research associates also participated in a two-day analysis workshop. This involved a team approach to identifying key themes from the interviews, which focussed on what was important to live a good life and how their lives could be improved and validation of some of the findings. It also gave them an opportunity to present emerging findings to the donors at the end of the workshop.

In 2016–18, ICED worked with the Queen Elizabeth Central Hospital (QECH) in Malawi to develop an intervention to improve uptake of ear and hearing services for children (Wilbur et al. 2018). A systematic review was conducted to identify possible strategies to increase access to services (Bright et al. 2017). In-depth interviews were undertaken with caregivers and children with hearing loss to identify barriers and facilitators to service uptake. A participatory workshop was held to use this information to develop strategies to improve uptake of specialist ear and hearing services, which is the focus of this case study. Two caregivers of children with hearing loss, staff from OPDs, healthcare workers and members of the Ministry of Health were invited to participate in the workshop. The findings of the formative research were discussed. Caregivers were asked to share their views on the findings and to contribute ideas that could address the barriers that they face in taking up the referral for their children. Their participation was crucial as part of the research was to design an intervention to improve service uptake.

However, it was apparent that the diversity of workshop participants (from Ministry of Health officials to specialist ear surgeons) meant that the caregivers did not always feel comfortable sharing their views with the wider group. These power imbalances may be particularly strong in LMICs. Moreover, the caregivers may not have been familiar with the structured approach taken in the workshop. We therefore held an additional focus group discussion with the caregivers who attended the workshop and two additional caregivers to provide a safe space to give their opinions and voice concerns about the formative research and to identify strategies for improving uptake.

We had anticipated that the intervention developed would relate to provision of transport to support uptake of services. However, the programme implementers were concerned that this would not be a sustainable intervention, and so a leaflet-based counselling intervention was developed with the collaboration of caregivers (Wilbur et al. 2018). This approach has been pilot-tested and shown to be feasible and appropriate (Baum et al. 2019) but not yet scaled due to lack of programmatic resources and policy priority.

The caregivers did not conduct data analyses themselves. We could have tried to identify researchers with shared experiences (e.g., with hearing loss), which may have helped to enrich our understanding of the data further, but these are often lacking in LMICs. Another option could have been to give caregivers their transcripts for comment or correction, although this would have been difficult due to the high levels of illiteracy in the area.

Another approach was used in Vanuatu as part of a project on the experiences of incontinence and MHM among people with disabilities (ICED 2020). Here, we involved people with disabilities in analysis of data collected through PhotoVoice, whereby participants are lent a camera, shown how to take photos and asked to take images of their experiences. With the photos in front of them, researchers interviewed participants about the issue they were conveying through the photos. Data interpretation was conducted by participants who crafted photo captions and ranked the images according to which issues were the most to least important. Photos provided information on the challenges faced by participants in relation to using products, accessing water, sanitation and hygiene and relying on caregivers, as well as the benefits of having accessible devices and being able to bathe independently.

Dissemination of data: Vanuatu and Brazil

Dissemination of research findings is critical to ensure that results can be used to influence policy and programmes. Here, too, the role of people with disabilities and their representative organisations is important.

In Vanuatu, PhotoVoice was used to support data dissemination as images and accompanying captions were displayed in a photo exhibition for the general public, donors, policy makers and implementers (ICED 2020). One PhotoVoice participant (with a mobility limitation) spoke first-hand about his experiences. He said that attendees appreciated the 'rawness' of the images, which were unlike polished images usually exhibited, and felt they brought the statistics and research findings to life and wanted to hear more about the experiences of the person who presented his photos. One PhotoVoice participant with a disability, who had incontinence and has since passed away, told his family that he was proud to be able to share his experiences through PhotoVoice (Wilbur et al. 2021). He hoped they would help others in a similar situation and that it would influence policy makers to improve the situation. His family were also proud that his images were included in a peer reviewed article.

Research findings continue to be disseminated together with the Rainbow Theatre, a group of Ni-Vanuatu actors with disabilities. In this dissemination, the Rainbow Theatre uses humour, drama, song and dance to disseminate the key findings in an engaging and powerful way. The plays will be filmed as six short skits and shown in communities where the research was conducted, shared in a blog/vlog series and used to advocate with stakeholders. We hope this will increase popular understanding how a lack of access to water, sanitation and hygiene (WASH) services impacts the lives of people with disabilities and their families, encourage people to reflect on their own views of disability, generate discussion between audiences and integrate disability within WASH activities in Vanuatu.

Another example of participatory dissemination comes from a project in Brazil about CZS, where mothers of children presented at workshops in Brazil and the UK and helped spread the messages through media (Kuper et al. 2019). These participatory dissemination activities reached policy makers and programme planners as they were panellists and audience members. Furthermore, two mothers co-authored a paper in an international journal on the research (Passos et al. 2020). Their views on the research process were important and insightful, but they would have lacked the academic skills to write the paper independently. Similarly, we have facilitated people with dementia to write a paper on research, which was co-authored by an academically skilled researcher without dementia (Davies et al. 2021).

Reflections and Discussion

In this paper, we reflected on different approaches used by ICED, a global research centre, to promote participation of people with disabilities in research in LMICs and the challenges experienced. We found that meaningful participation of people with disabilities throughout the stages of the research cycle is possible and may improve the quality of research. It is also empowering for people with disabilities who are genuinely involved and included. There were some examples from our work as to how participatory approaches led to the development of more appropriate and relevant programmes (Baum et al. 2019; Duttine et al. 2019; Wilbur et al. 2019). The potential impact in informing policy was not explored and requires more attention. Below, we consider issues around participatory approaches, how participatory research can be improved further and how it can be used to influence policy and programme development.

Lessons learnt for participatory research

There were some common lessons across these LMIC case studies about the practicalities of undertaking participatory research. People with disabilities were able to advise on which data collection tools and methods are most acceptable and relevant. Furthermore, data collected by people with disabilities is possible and may be of higher quality, as research participants appeared more willing to talk more openly and in-depth with disabled researchers as we and others have found (Bhatta et al. 2018; Davies et al. 2021; Pinfold et al. 2015; Wilbur et al. 2019), although this needs further exploration (Holland et al. 2008). People with disabilities could also participate in the dissemination of results, particularly to other community members (ICED 2020). Less consistent participation was achieved in setting the research question and analysis. It appears from our case studies that each achieved the higher rungs of the ladder of participation for specific aspects of research but not for the entire study. Co-produced or emancipatory research was only achieved throughout when it was led by a disabled researcher from the ICED team. Other researchers have also noted that the ease of participation varies at different points in the research cycle. For instance, the LEAP project found that co-production worked best in the development of study materials but did not work well in research design (Pinfold et al. 2015). In contrast, they needed to make considerable effort and investment to achieve reasonable levels of co-production during analysis and dissemination (Pinfold et al. 2015). Lack of participation may be particularly profound in LMICs, where the available pool of skilled disabled researchers is smaller.

Consideration needs to be given to who was participating. Certain groups (e.g., people with physical impairments, carers) were more likely to participate while others (e.g., people with intellectual impairments) were less likely to be included. Several of our case studies focussed on parents of children with disabilities, which is arguably not participatory research. Participation of disabled children may be particularly neglected, and consequently we are failing to capture their opinions and experiences (Wickenden & Elphik 2016; Wickenden & Kembhavi 2014). Other researchers agree that participation privileges certain groups (Holland et al. 2008) and is potentially more challenging for people with certain impairment types, such as people with intellectual disabilities (Nind et al. 2016). Do we consider it participation if, as in our experience in India, researchers with physical impairments were included for interviews of people with other impairment types? There may have also been gender and education dynamics operating to influence who was included as a disabled researcher and who continued to be excluded. People with disabilities are also not homogenous in experience and opinions and will have different views on issues, such as assistive living or special versus inclusive education (Minkler et al. 2002). Consequently, more attention needs to be given to including a wider range of disabled researchers, in particular researchers with learning and communication impairments, and this may require adoption or development of new tools and methods (e.g., visual methods and observation) (Aldridge 2007; Wickenden & Elphik 2016; Wickenden & Kembhavi 2014). Yet again, opportunities may be particularly limited for this approach in LMICs.

Planning for inclusion must occur from the start of the research cycle and must be adequately resourced in both money and time to ensure that appropriate accommodations are in place. Obvious accommodations include tackling practical issues, such as producing research materials in accessible formats, ensuring that venues are accessible and providing sign language interpretation. However, accommodations need to go beyond considerations of accessibility and language interpretation to encompass introducing more flexibility into the academic environment and research methods (Mellifont et al. 2019). For instance, the Dementia Enquirers highlighted the need to adapt mainstream research practices (e.g., taking more breaks) and governance (e.g., simplifying ethics submissions) in order to support participatory research. Vaughan and colleagues (2019) from Australia note further that

People with disabilities are not a homogeneous group, and bring contrasting perspectives, life experiences, and experiences of disability to any research encounter. Facilitating an inclusive process must include creating the time and space necessary to negotiate difference.

Ethical issues must also be considered, such as ensuring that participation is voluntary and appropriately reimbursed, particularly as financial pressures may act as a barrier to participation in research. It is, of course, important to respect confidentiality and consent, particularly when undertaking research with disabled children or adults with cognitive impairments (Wickenden & Kembhavi 2014). However, it must be ensured that researchers don't veer towards overprotection. The Dementia Enquirers described themselves as '...victims of paternalism, in the name of ethics', for instance at the need for a relative to be included in an interview. Blanket restrictions or rules may therefore be exclusionary—in this example, not all people with dementia are the same.

Certain aspects of participatory research remained challenging in our case studies, which may reflect issues for the conduct of this research approach in LMICs more broadly. For example, involving people with disabilities and OPDs in setting the research question was often difficult, as this requires knowledge of the evidence base and an understanding of what kinds of questions research can and cannot be answered. As an example, one OPD consulted wanted to study gender in relation to disability and needed support to develop a more specific and achievable research question. Furthermore, developing grant applications is often unfunded, making in-depth preparatory consultation with people in LMICs more challenging as time and budget are limited. Strengthening requirements by donors for evidence of participation at the application stage may be helpful. Another mechanism to ensure participation in establishing the

research question is to include disabled members on the steering group, as we did in our study in the Gaza Strip. Both the DRILL programme and the Dementia Enquirers programme are other good examples (Berry et al. 2020; Davies et al. 2021; DRILL 2020). It is important that this role is not tokenistic, and so the steering group members must be given the relevant information to be able to make informed contributions. Ideally, they should also be compensated for their time, which may be an important consideration of OPD members in LMICs. Furthermore, including only one member with disabilities may be insufficient; whereas, having several disabled members can help to overcome entrenched power differentials between different actors. 'People with disabilities' describes an extremely heterogeneous group, and attempts to expand participation must ensure that this diversity is reflected, including factors such as gender, age, limitation type and socioeconomic status.

Participatory analysis was another challenging area in our case studies as it requires particular expertise and skills and the pool of skilled disabled researchers in LMICs is lacking. Academics may also resist losing their role as experts, which is potentially more apparent in analysis compared to data collection (Nind 2011). Specific training and capacity development of people with disabilities is, of course, possible, with respect to analytical methods in particular and research methods more broadly (Pinfold et al. 2015), and may be particularly important to close gaps in LMICs. Here, we can think beyond traditional taught courses to also consider other models, such as apprenticeships or mentorships with experienced researchers or joint learning programmes for researchers and people with disabilities (Nind et al. 2016) as we implemented in our study in Nepal. ICED also holds a work experience scheme for people with disabilities interested in learning about research, and in 2020, we started a PhD scheme for African researchers with disabilities looking to develop research skills with our support and experience. We could also consider that a focus on participation in formal data analysis is too narrow and give more value to analytical approaches within the data collection phase (Holland et al. 2008) or the importance of discussion of findings, where the participant could be the 'sense-maker' of data and the formal academic the mentor or facilitator (Nind 2011). This approach was used in our Colombia and Nepal case studies. There is also a question as to whether participatory analysis is necessarily unquestionably a good thing. For instance, one author noted that young people with disabilities did not always want to take part in the formal data analysis (Holland et al. 2008). There are also ethical considerations where people have shared personal information and this is then disclosed as others in the group are involved in the analysis of data (Nind 2011).

Participatory methods essentially involve moving power from the researcher to the research participants, which some researchers and funders may resist. An additional issue in research in LMICs is that not only does the power dynamic have to be overcome between the academic and the non-professional disabled researcher, but also between people from LMIC and high-income settings if researchers from both contexts are included in the study. Different actors may also experience different motivations and pressures (Vaughan et al. 2019). For instance, academics are under pressure to publish and gain recognition in the university and from other academics. Meanwhile, people with disabilities participating in research, who are not formal academics, may be more concerned about the financial pressures of getting involved in research (e.g., taking time away from work, travel costs), and they may feel that they are taking greater risks by making themselves vulnerable by revealing personal information and sharing their stories. The benefits may also be different: disabled researchers may develop practical skills, improved self-confidence and strengthened social networks; whereas, the academics may focus more on gaining university career advancement and improving academic knowledge. Time pressures may differ too as academics acknowledge that generating and publishing information takes time; whereas, disabled non-academics may want to see impact faster.

These considerations raise a broader question as to whether we should always aim for the highest rung in the ladder of emancipatory research. Some would argue yes—as the social model puts the case that disability arises through oppression and, consequently exclusion from research carries this oppression into evidence generation (Nind 2011). However, research requires particular skills that take years of training to develop. Even with training, people with certain impairments (e.g., people with profound learning or cognitive impairments) may struggle to be independent researchers. There may also be unintended negative consequences of training itself, as described by Nind and colleagues (2016): 'The conundrum is that if, as inclusive researchers, we value differences, then we should not inadvertently train them away and thereby lose the very sense of differences in dialogue that we were seeking'. The ladder also does not consider the positive contributions of the non-disabled research partners, who may be highly skilled, or the ethical issues of excluding people without disabilities. Of course, non-disabled researchers should be encouraged to reflect on their position, power and attitudes towards disabled researchers, making sure that they neither over- or under-estimate the abilities and skills of a disabled co-researcher (Callus 2019). Perhaps what is important is a commitment to solidarity and mutual support and cooperation towards a common goal (Vaughan et al. 2019) or co-produced research, rather than necessarily on the achievement of emancipatory research. This solidarity is to respect that '...working in partnership meant doing things together (reading, writing, talking) *and* doing things separately in tasks allocated according to people's strengths, knowledge or interests' (Nind 2017). To this end, it would be helpful to undertake further formal evaluation of co-production methods and tools to identify which should be recommended and what gaps remain that should be filled.

We identified some examples in our portfolio of work from LMICs of how participatory research appeared to lead to better evidence and more appropriate intervention design (Baum et al. 2019; Duttine et al. 2019; Wilbur et al. 2019). However, participatory research will not in and of itself lead to change in programme or policy uptake, and

additional steps are needed to facilitate this process. Lessons can therefore be learnt from participatory research on how to overcome challenges to participatory programme planning or policy-making, such as planning and resourcing for participatory processes from the start, addressing hierarchies between users and service providers to foster participatory approaches, supporting open and inclusive communication and building capacity of people with disabilities to take part in this process, (Kleintjes et al. 2010; Ottmann & Laragy 2010). OPDs often play a strong role in advocacy, and their role in fostering policy change can be further strengthened through these approaches.

Conclusion

The importance of participation of people with disabilities in all activities that relate to their interests is well-recognised. However, participatory research is not yet the dominant approach, particularly in LMICs. Meaningful participation requires shifting power from high income researchers to people with disabilities and researchers in LMICs, and this requires commitment, planning and adequate resourcing. Development of tools and guidance to inform and monitor participation, such as the scoring system developed by the LEAP project, (Pinfold et al. 2015), may also be helpful. The benefits of participatory research are not only that it is equitable and respectful, but also that it can potentially produce higher quality evidence that is better able to drive appropriate programmes and policy changes to improve the lives of people with disabilities. Above all, it is the right thing to do (Holland et al. 2008).

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Competing Interests

The authors have no competing interests to declare.

Author Contributions

HK and TS conceptualised the paper, and HK wrote the first draft. SH, VR, NS, JW, MZ, IM, TB and TS each wrote a case study. All authors reviewed and agreed the final text.

References

- Albert, Bill, and Mark Harrison. 2005. "Messages from research: Disability knowledge and research (KaR) programme." Norwich, UK: University of East Anglia.
- Aldridge, J. 2007. "Picture this: the use of participatory photographic research methods with people with learning disabilities." *Disability & Society* 22(1): 1–17. DOI: <https://doi.org/10.1080/09687590601056006>
- Arnstein, S. 1969. "A ladder of citizen participation." *Journal of the American Institute of Planners* 35: 216–24. DOI: <https://doi.org/10.1080/01944366908977225>
- Barnes, Colin. 2003. "What a difference a decade makes: Reflections on doing 'emancipatory' disability research." *Disability & Society* 18(1): 3–17. DOI: <https://doi.org/10.1080/713662197>
- Baum, A., W. Mulwafu, M. Phiri, S. Polack, and T. Bright. 2019. "An Intervention to Improve Uptake of Referrals for Children with Ear Disease or Hearing Loss in Thyolo District, Malawi: Acceptability and Feasibility." *Int J Environ Res Public Health* 16(17). DOI: <https://doi.org/10.3390/ijerph16173144>
- Berghs, Maria. 2017. *Emancipatory Engagement and Co-Production: Disability Research for Activism*. London. Retrieved from <https://methods.sagepub.com/case/emancipatory-engagement-and-co-production-disability-research-for-activism>. DOI: <https://doi.org/10.4135/9781473950139>
- Berry, Peter, Teresa Davies, Carol Fordyce, Howard Gordon, Philly Hare, Agnes Houston, Rachael Litherland, Mhari McLintock, Wendy Mitchell, and Tracey Shorthouse. 2020. "Dementia Enquirers—People with dementia in the driving seat of research." *Dementia* 19(1): 68–73. DOI: <https://doi.org/10.1177/1471301219876506>
- Bhatta, C., S. Bhujel, S. Dhakal, N. Gyawali, M. K. Shah, S. Shrestha, A. Sigdel, et al. 2018. "Strengthening the voices of adolescents with disabilities in Nepal." UK: ICED.
- Bright, T., L. Felix, H. Kuper, and S. Polack. 2017. "A systematic review of strategies to increase access to health services among children in low and middle income countries." *BMC Health Serv Res* 17(1): 252. DOI: <https://doi.org/10.1186/s12913-017-2180-9>
- Callus, Anne-Marie. 2019. "Being an inclusive researcher: Seeking questions, raising answers." *Disability & Society* 34(7–8): 1241–63. DOI: <https://doi.org/10.1080/09687599.2019.1602511>
- Charlton, J. I. 1998. *Nothing about us without us: Disability oppression and empowerment*. Berkeley, CA: University of California Press. DOI: <https://doi.org/10.1525/9780520925441>
- Danieli, Ardha, and Carol Woodhams. 2005. "Emancipatory research methodology and disability: A critique." *International Journal of Social Research Methodology* 8(4): 281–96. DOI: <https://doi.org/10.1080/1364557042000232853>
- Dassah, E., H. M. Aldersey, and K. E. Norman. 2017. "Photovoice and Persons With Physical Disabilities: A Scoping Review of the Literature." *Qualitative Health Research* 27(9): 1412–22. DOI: <https://doi.org/10.1177/1049732316687731>

- Davies, Teresa, Agnes Houston, Howard Gordon, Mhari McLintock, Wendy Mitchell, George Rook, and Tom Shakespeare. 2021. "Dementia enquirers: Pioneering approaches to dementia research in UK." *Disability & Society*, 1–19. DOI: <https://doi.org/10.1080/09687599.2021.1916887>
- DRILL. "Disability research on independent living and learning." Retrieved from <http://www.drilluk.org.uk/>.
- Duttine, A., T. Smythe, M. R. Calheiro de Sa, S. Ferrite, M. E. Moreira, and H. Kuper. 2019. "Development and assessment of the feasibility of a Zika family support programme: A study protocol." *Wellcome Open Res* 4: 80. DOI: <https://doi.org/10.12688/wellcomeopenres.15085.1>
- Greenwood, Margo. 2016. "Hear my voice: A community-based participatory study gathering the lived experiences of people with disabilities and older people in Tanzania." *Knowledge Management for Development Journal*, 63–78.
- Greenwood, Margo. 2017. "Participatory research and the SDGs: What is Sightsavers doing?" *Sightsavers*. Retrieved from <https://www.sightsavers.org/blogs/2017/03/participatory-research-sightsavers/>.
- Hickey, Gary. 2018. "The potential for coproduction to add value to research." *Health Expectations* 21(4):693. DOI: <https://doi.org/10.1111/hex.12821>
- Holland, S., E. Renold, N. Ross, and A. Hillman. 2008. "Rights, 'right on' or the right thing to do? A critical exploration of young people's engagement in participative social work research." Cardiff: Cardiff University.
- ICED. 2020. "Water, women and disability study." London: ICED.
- Institute of Development Studies. "Participatory methods website." Institute of Development Studies. Retrieved from <https://www.participatorymethods.org/>.
- Kleintjes, S., C. Lund, L. Swartz, and A. Flisher. 2010. "Mental health care user participation in mental health policy development and implementation in South Africa." *Int Rev Psychiatry* 22(6): 568–77. DOI: <https://doi.org/10.3109/09540261.2010.536153>
- Kuper, H., T. M. Lyra, M. E. L. Moreira, M. d. S. V. de Albuquerque, T. V. B. de Araújo, S. Fernandes, M. Jofre-Bonet, et al. 2019. "Social and economic impacts of congenital Zika syndrome in Brazil: Study protocol and rationale for a mixed-methods study." *Wellcome Open Research* 3(127). DOI: <https://doi.org/10.12688/wellcomeopenres.14838.1>
- Lang, Raymond, Marguerite Schneider, Maria Kett, Ellie Cole, and Nora Groce. 2019. "Policy development: An analysis of disability inclusion in a selection of African Union policies." *Development Policy Review* 37(2): 155–75. DOI: <https://doi.org/10.1111/dpr.12323>
- Lunch, Nick, and Chris Lunch. 2006. *Insights into participatory video: A handbook for the field*. InsightShare.
- Mactaggart, I., H. Kuper, G. V. Murthy, J. Oye, and S. Polack. 2016. "Measuring Disability in Population Based Surveys: The Interrelationship between Clinical Impairments and Reported Functional Limitations in Cameroon and India." *PLoS One* 11(10): e0164470. DOI: <https://doi.org/10.1371/journal.pone.0164470>
- Mellifont, Damian, Jennifer Smith-Merry, Helen Dickinson, Gwynnyth Llewellyn, Shane Clifton, Jo Ragen, Martin Raffaele, and Paul Williamson. 2019. "The ableism elephant in the academy: A study examining academia as informed by Australian scholars with lived experience." *Disability & Society* 34(7–8): 1180–99. DOI: <https://doi.org/10.1080/09687599.2019.1602510>
- Minkler, M., P. Fadem, M. Perry, K. Blum, L. Moore, and J. Rogers. 2002. "Ethical dilemmas in participatory action research: A case study from the disability community." *Health Educ Behav* 29(1): 14–29. DOI: <https://doi.org/10.1177/109019810202900104>
- Nind, M., R. Chapman, J. Seale, and L. Tilley. 2016. "The Conundrum of Training and Capacity Building for People with Learning Disabilities Doing Research." *J Appl Res Intellect Disabil* 29(6): 542–51. DOI: <https://doi.org/10.1111/jar.12213>
- Nind, Melanie. 2011. "Participatory data analysis: A step too far?" *Qualitative Research* 11(4): 349–63. DOI: <https://doi.org/10.1177/1468794111404310>
- Nind, Melanie. 2017. "The practical wisdom of inclusive research." *Qualitative Research* 17(3): 278–88. DOI: <https://doi.org/10.1177/1468794117708123>
- Ottmann, G. F., and C. Laragy. 2010. "Developing consumer-directed care for people with a disability: 10 lessons for user participation in health and community care policy and program development." *Aust Health Rev* 34(4): 390–4. DOI: <https://doi.org/10.1071/AH09759>
- Passos, M. J., G. Matta, T. M. Lyra, M. E. L. Moreira, H. Kuper, L. Penn-Kekana, and M. Mendonça. 2020. "The promise and pitfalls of social science research in an emergency: Lessons from studying the Zika epidemic in Brazil, 2015–2016." *BMJ Glob Health* 5(4). DOI: <https://doi.org/10.1136/bmjgh-2020-002307>
- Photovoice. "Photovoice." Retrieved from <https://photovoice.org/>.
- Pinfold, Vanessa, Paulina Szymczynska, Sarah Hamilton, Richard Peacocke, Shirley Dean, Naomi Clewett, Jill Manthorpe, and John Larsen. 2015. "Co-production in mental health research: Reflections from the People Study." *Mental Health Review Journal* 20(4): 220–31. DOI: <https://doi.org/10.1108/MHRJ-09-2015-0028>
- Shakespeare, Tom, Anthony Mugeere, Emily Nyariki, and Joseph Simbaya. 2019. "Success in Africa: People with disabilities share their stories." *African Journal of Disability (Online)* 8: 1–7. DOI: <https://doi.org/10.4102/ajod.v8i0.522>

- Smythe, T., M. Matos, J. Reis, A. Duttine, S. Ferrite, and H. Kuper. 2020. "Mothers as facilitators for a parent group intervention for children with Congenital Zika Syndrome: Qualitative findings from a feasibility study in Brazil." *PLoS One* 15(9): e0238850. DOI: <https://doi.org/10.1371/journal.pone.0238850>
- UN. 2006. "Convention on the rights of persons with disabilities." New York: United Nations.
- Vaughan, Cathy, Sarah Khaw, Georgia Katsikis, Jacinta Wheeler, Jasmine Ozge, Vasiliky Kasidis, and Lila Moosad. 2019. "It is like being put through a blender': Inclusive research in practice in an Australian university." *Disability & Society* 34(7–8): 1224–40. DOI: <https://doi.org/10.1080/09687599.2019.1603103>
- Whitzman, Carolyn, Kathryn James, and Ipul Poweseu. 2013. "Travelling together: Participatory research methods for disability inclusive road development in Papua New Guinea." *Journal of Transport Geography* 26: 65–71. DOI: <https://doi.org/10.1016/j.jtrangeo.2012.09.001>
- Wickenden, M., and J. Elphik. 2016. "Don't forget us, we are here too! Listening to disabled children and their families living in poverty." In *Disability in the Global South: The Critical Handbook*, edited by S. Grech and K. Soldatic, 167–85. Switzerland: Springer. DOI: https://doi.org/10.1007/978-3-319-42488-0_11
- Wickenden, M., and G. Kembhavi. 2014. "Ask us too! Doing participatory research with disabled children in the global south." *Sociology, Gender Studies & Cultural Studies* 21(3): 400–17. DOI: <https://doi.org/10.1177/0907568214525426>
- Wilbur, J., C. Morrison, L. Bamberg, J. Tanguay, S. Baker, P. Sheppard, J. Shem, J. Iakavai, R. Poilapa, and I. Mactaggart. 2021. "I'm scared to talk about it': Exploring experiences of incontinence for people with and without disabilities in Vanuatu, using mixed methods." *Lancet Regional Health – Western Pacific* 14. DOI: <https://doi.org/10.1016/j.lanwpc.2021.100237>
- Wilbur, J., T. Bright, T. Mahon, S. Hameed, B. Torondel, W. Mulwafu, H. Kuper, and S. Polack. 2018. "Developing Behaviour Change Interventions for Improving Access to Health and Hygiene for People with Disabilities: Two Case Studies from Nepal and Malawi." *International Journal of Environmental Research & Public Health [Electronic Resource]* 15(12): 05. DOI: <https://doi.org/10.3390/ijerph15122746>
- Wilbur, J., T. Mahon, B. Torondel, S. Hameed, and H. Kuper. 2019. "Feasibility Study of a Menstrual Hygiene Management Intervention for People with Intellectual Impairments and Their Carers in Nepal." *Int J Environ Res Public Health* 16(19). DOI: <https://doi.org/10.3390/ijerph16193750>

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